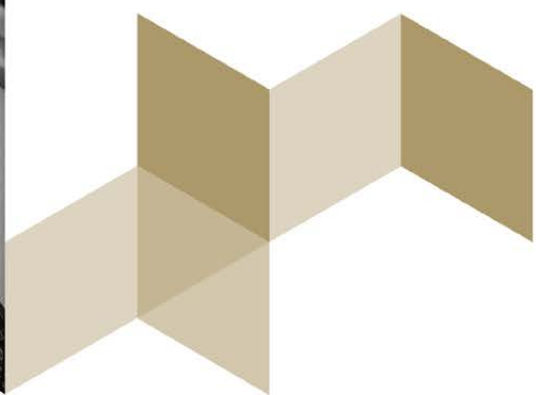


Celebrating 25 years of Club Rainbow (Singapore)

**EMBRACE
ENABLE
EMPOWER**



Club Rainbow (Singapore)



VISION

To be the charity of choice that inspires hope and makes a difference in the lives of children with chronic illnesses and their families.

MISSION

We support and empower children with chronic illnesses & their families by providing compassionate relevant services in their journey towards an enriching life.

VALUES

Teamwork, Professionalism, Respect, Integrity, Compassion & Excellence.

2017 marks the 25th year anniversary of Club Rainbow (Singapore)!

Our history dates back to 1991 when members of Rotaract Club of Singapore came together to organise Camp Rainbow, a medically supervised residential camp for children with various chronic and life-threatening illnesses. Following the success of the camp, Club Rainbow (Singapore) was set up in 1992 to further provide a comprehensive range of support services for children with chronic illnesses. From initially covering six illnesses, we now extend our reach to cover all chronic illnesses.

The past few years has seen a major transition in leadership and in 2016, a new vision and mission was put together to steer Club Rainbow (Singapore) towards greater heights. Armed with the vision of being the charity of choice that inspires hope and makes a difference, we currently serve more than 800 Rainbow children and their families. It is our mission to support and empower children with chronic illnesses & their families by providing compassionate relevant services in their journey towards an enriching life. With this in mind, we continually work towards improving and expanding our pool of services as well

as the number of children and families served. We also strive to champion accountability and transparency in our management and operations.

Club Rainbow (Singapore) adopts a holistic approach by providing services in 5 core aspects – Emotional Support, Financial Support, Educational Assistance, Social Integration and Informational Resources; some of which include home and hospital counselling as well as tuition services, social integration programmes, financial subsidies and educational learning journeys. We also provide a range of therapy services such as physiotherapy, occupational therapy, art and play therapy. Free transport service is also offered to beneficiaries with mobility issues.

Moving forward, we will be rolling out new initiatives with focus on social integration, bridging for graduating beneficiaries and support for caregivers. Social Integration programmes and events are organised throughout the year and calibrated towards strengthening family ties, talent development and community engagement. A revamp of the BRIDGE programme, for those between ages 16 to 20 years, will equip graduating beneficiaries with the necessary skills

and knowledge to ensure a smooth transition to adulthood. For caregivers, a holistic respite care will be rolled out to allow caregivers rest and temporary relief from caregiving duties. In addition, informational resources to effectively care for their child will also be provided.

We have also anchored two annual fund-raising events - Ride for Rainbows and Climb for Rainbows to generate public awareness about Club Rainbow (Singapore) and raise funds needed in our provision of compassionate relevant services to our Rainbow children and their families.

Club Rainbow (Singapore) has been blessed to receive tremendous support over the years. We would like to extend our warmest gratitude to our individual and corporate donors, partners and sponsors whose generous contributions are integral to our work. These contributions go a long way towards the provision of daily necessities and services for our Rainbow children and families as well as the running of our day-to-day operations. We thank you and look forward to your continued support. Our heartfelt thanks also go out to our Advisory Board, members, Management

Council members, staff and volunteers who have dedicated their time to serve and touch the lives of our Rainbow children.

On behalf of Club Rainbow (Singapore), I would like to say a BIG thank you to all our Rainbow children and their families for allowing us the opportunity to serve you. We embrace this responsibility as we believe each child entrusted under our care is precious. It is our hope to leave a lasting impact by empowering each Rainbow child to live an enriched life even after graduating from Club Rainbow (Singapore). To all caregivers, we are inspired by your unwavering dedication to caring for your child. Thank you for being part of the Rainbow family; it is our privilege to journey together with you.

To commemorate our 25th year anniversary, we have put together a special coffee table book that captures the heartbeat of Club Rainbow (Singapore) through 20 unique stories of our Rainbow children.

As you flip through the pages of this book, we hope the stories touch your heart and stir up a deep compassion for the lives of our Rainbow

children and their families. Indeed the golden thread of resilience and hope is woven through the tapestry of these 20 remarkable stories.

EMBRACE – We embrace each child as unique and precious in our Rainbow family.

ENABLE - We enable our Rainbow children to manage their chronic illnesses by equipping them with necessary skills and resources.

EMPOWER – We empower our Rainbow children to rise above their illnesses by building resilience and confidence to better handle challenges and lead enriching lives.

We hope you enjoy the stories and warmly welcome you onboard our Rainbow journey to embrace, enable and empower!

Sincerely yours,

Dr. Sashikumar Ganapathy
President
Club Rainbow (Singapore)

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ABOUT CLUB RAINBOW (SINGAPORE)

Embrace, Enable and Empower

Club Rainbow (Singapore)



Set up in 1992, Club Rainbow (Singapore) is a non-profit organisation with a mission to support and empower children with chronic illnesses & their families by providing compassionate relevant services in their journey towards an enriching life.

Children in Club Rainbow (Singapore) range from new-borns to youths up to the age of 20. Many of whom require frequent hospital visits for treatment, therapy and long-term medication. Club Rainbow (Singapore) works closely with KK Women's & Children's Hospital (KKH), the National University Hospital (NUH) and the neonatal unit of Singapore General Hospital (SGH). On recommendation of doctors, the children are referred to Club Rainbow (Singapore) for critical follow-up support.

Armed with the vision to be the charity of choice that inspires hope and makes a difference in the lives of children with chronic illnesses and their families, Club Rainbow (Singapore) adopts a holistic approach to help our beneficiaries in five core aspects:

- Emotional Support
- Financial Support
- Educational Assistance
- Social Integration
- Informational Resources

We offer an array of free support services to our beneficiaries in each core aspect, some of which include home and hospital counselling as well as tuition services, regular social integration programmes and educational seminars.

Underscoring the work that we do are our core values:

Teamwork | Professionalism | Respect | Integrity | Compassion | Excellence

Club Rainbow (Singapore) is an independent charity that relies largely on corporate and public donations to support our mission and sustain our work and daily operations.

Club Rainbow (Singapore) is a full member of the National Council of Social Services and we are registered under the Registry of Societies and Commissioner of Charities. We have also been given the Institute of Public Character (IPC) status by the Ministry of Health. The IPC status enables Club Rainbow (Singapore) to provide tax-exemption receipts for monetary donations received.

MAJOR ILLNESSES AFFECTING

CHILDREN IN CLUB RAINBOW (SINGAPORE)

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

BLOOD DISORDERS

Blood disorders result from the defects in blood vessels or abnormalities in the blood itself. Common blood disorders serviced by Club Rainbow (Singapore) include **Haemophilia** (bleeding disorder), **Thalassaemia Major** (inheritable disorder where abnormal haemoglobin is produced, affecting oxygen transport around the body) and **Anaemia** (abnormally low red blood cell count).

CARDIOVASCULAR DISEASE

Congenital Heart Disease (CHD) is an abnormality in one's heart structure and great vessels since birth. It is the single most common major congenital abnormality. Most heart defects obstruct blood flow in the heart in an abnormal way. Many undergo corrective surgery and are able to survive into adulthood.

GASTROENTEROLOGY

Gastroenterology relates to disorders of the gastrointestinal tract, liver and pancreas. Club Rainbow (Singapore) services a high number of beneficiaries with **Biliary Atresia (BA)**. BA is a disease characterised by the absence of bile ducts, which normally drain bile from the liver to the intestines. Many have to undergo surgery (Kasai Procedure) which involves connecting a segment of intestine to the liver's bile ducts to re-establish the flow of bile away from the liver. A third may survive to early childhood but suffer from liver failure. Eventually a liver transplant will be the optimal but is costly and involves risk/complications.

NEUROLOGIC DISORDERS

Neurologic disorders affect the body's nervous systems. Some symptoms include paralysis, muscle weakness and poor coordination. **Cerebral Palsy** (movement disorders that appears in early childhood) and **Muscular Atrophy/Dystrophy** (progressive loss of mass/weakness muscle mass) are common diagnosis affecting mobility of a child. From the spectrum of disorders, one of the most severe is **Duchenne Muscular Dystrophy (DMD)**. Some affected children never learn to walk, while some gradually get weaker and lose their ability to even stand or walk. Most children are either wheelchair-bound or bedridden. One of the most severe complications is when they become too weak to use their muscles to breathe adequately, eventually entering into respiratory failure. Without proper respiratory support, many at this stage will suffer from frequent chest infections and also succumb to the illness.

VERY LOW BIRTH WEIGHT INFANTS

Very low birth weight infants born with weights (<1500g) and premature, which is less than 37 weeks gestation is common in Singapore. Although there are cases of premature babies as early as 24 weeks of gestation being saved, more complications are faced due to insufficient development of their organ systems. Most babies will encounter various combinations of respiratory, cardiovascular, neurological, visual and nutritional problems.

RENAL DISORDERS

Children as young as infants can develop kidney failure. When the kidneys fail to excrete unwanted toxic metabolites and excess water at a sufficient rate, both fluid and dangerous waste products accumulate in the body. When the kidneys completely cease to function, the child is in **End Stage Renal Failure (ESRF)** and requires lifelong dialysis, unless a kidney transplant can be arranged. **Nephrotic Syndrome** disease involves the kidneys in which there is leakage of a large amount of proteins from the kidneys into the urine. This result in a disruption in the distribution of the body's fluid balance and a child with Nephrotic Syndrome will appear swollen in the face, abdomen and the limbs due to fluid accumulation. Most will require long-term steroid medication and many will suffer from their side effects.

RARE SYNDROME/GENETIC DISORDERS

A genetic disorder is caused by abnormal expression of one or more genes in a person. There are a number of possible causes for genetic defects, ranging from mutation of a gene, abnormal chromosome number and other causes. The vast majority of these disorders are quite rare and affect one in several thousands or millions of people. The group consists of genetic disorders such as **Williams Syndrome**, **Angelman Syndrome**, **Prader-Willi Syndrome** and **Velocardiofacial Syndrome**.

OTHERS

METABOLIC DISORDERS

Diabetes Mellitus (DM) is a metabolic disorder where the body has high blood sugar levels over a prolonged period. It is further segregated into Type 1 and Type 2. DM Type 1 results from the pancreas's failure to produce enough insulin and is more common in children. DM Type 2 is where cells fail to respond to insulin produced by the body. Insulin is the hormone necessary to control the body's sugar level. These children require long-term daily treatment consisting of multiple insulin injections, and frequent finger pricks to monitor their blood sugar level. However, despite treatment, both short and long term complications may still arise.

IMMUNOLOGICAL DISORDERS

Immunological disorder is a dysfunction of the immune system. Frequent occurring disorders include: **Systemic Lupus Erythematosus (SLE)** which is an autoimmune disease where the body's immune system attacks healthy tissue. Affected areas can be the skin, joints, kidneys, brains and other organs. **Juvenile Arthritis** results in the inflammation of joints. **Chronic Eczema** is prolonged inflammation of the skin leading to rashes, dryness and blistering of the skin.

RESPIRATORY DISEASE

Asthma is a common long term inflammatory disease of the airways of the lungs. Symptoms include episodes of wheezing, coughing, chest tightness and shortness of breath. With medical advancement, most cases can be controlled with medication.



EMOTIONAL SUPPORT

Casework and Counselling is one of Club Rainbow (Singapore)'s core services to support children with chronic illnesses and their families.

It aims to:

- help families cope with their child's chronic illness
- enhance individual personal growth by equipping one with necessary coping and problem solving skills to meet his/her basic needs
- attend to the psychosocial needs of the families and assist them to work towards resilience

When a child is referred and accepted as a Club Rainbow (Singapore) beneficiary, a caseworker is assigned to provide the beneficiary and his/her family with psychosocial support. The interventions and support extended to each family is unique and can be multi-faceted as it is dependent on the illness, severity of the chronic condition, developmental needs as well as the ability of the family to cope with the situation. The caseworker helps beneficiaries and their families learn how to manage life crisis due to the chronic medical conditions and focus on improving their mental and physical well-being to achieve self-reliance.



FINANCIAL SUPPORT

Club Rainbow (Singapore) provides short-term and interim financial assistance, both monetary and in-kind, to low-income families with the eventual aim of helping them attain resilience and self-reliance. This is achieved by providing emotional and psycho-social support, empowering them with positive coping and budgeting skills, maximising their limited resources and enhancing their personal growth. It is usually in the form of cash, in-kind items, grocery vouchers or therapy service subsidies.



EDUCATIONAL ASSISTANCE BURSARY AND AWARDS

To ease the financial burden of families in meeting their child's educational needs, the Rainbow Academic Support Program gives out Education Awards during the academic year to help low-income families as well as to recognise the efforts of Club Rainbow (Singapore) children and youths who have performed well in school despite their medical conditions. Bursaries are also offered to beneficiaries from low-income families who have done reasonably well in schools.

TUITION

With the help of dedicated volunteers, Club Rainbow (Singapore) runs a weekly tuition service on Saturdays to provide academic support to our beneficiaries. Tuition is also provided at KKH and NUH to beneficiaries who are hospitalised or at the hospitals seeking medical treatment.

ENRICHMENT WORKSHOPS

Enrichment workshops and experiential learning journeys are organised for our beneficiaries during the school holidays. The primary objective of the workshops and learning journeys is to help our beneficiaries to build strong self-esteem and develop life skills that will enable them to achieve their goals and pursue excellence.



SOCIAL INTEGRATION

Social integration programmes are a medium to incorporate balance in the physical and emotional aspects of a child's life. The aim is to provide equitable opportunities to enable and empower our children and families through:

- STRENGTHENING FAMILY TIES
- TALENT DEVELOPMENT
- COMMUNITY ENGAGEMENT



INFORMATIONAL RESOURCES

Club Rainbow (Singapore) conducts seminars and workshops by medical practitioners and professionals who share their knowledge to beneficiaries, parents and caregivers. Topics range from caring for children with specific needs, managing a chronic illness, new research and treatments, stress management, handling finances and nutrition care.



OTHER SUPPORT SERVICES THERAPY SERVICES

In Club Rainbow (Singapore), we strive to enhance our support for the health and emotional well-being of our beneficiaries. We do this through providing services such as Physiotherapy, Occupational Therapy, Speech Therapy, Play Therapy, Art Therapy and Swimming.

TRANSPORT

Club Rainbow (Singapore) provides free transportation service for beneficiaries with mobility-related disabilities that restrict them from taking public transport. The vans enable our beneficiaries to commute to and fro for hospital appointments, therapy and counselling sessions at our centres, swimming lessons and Club Rainbow (Singapore) programme and events.

RAINBOW CARE AND RESOURCE CENTRES (RCRC)

The Rainbow Care and Resource Centres are located at the KK Children's and Women Hospital (KKH) and National University Hospital (NUH). Weekly collaborations are done with volunteers and hospital staff to provide art and craft sessions, play sessions, board games sessions and tuition for our beneficiaries who are hospitalised or seeking treatment at the hospitals. Events and workshops are also organised at our centres with corporate partners. These activities serve to promote fun, social interaction and most importantly, help our beneficiaries manage the stress brought about by their illnesses.

SIGNATURE EVENTS



Climb for Rainbows



Dreamseeds Arts Fest



Club Rainbow staff



Climb for Rainbows



Dreamseeds Arts Fest



Ride for Rainbows



Annual Party



Arts Fest



Camp Rainbow



Annual Party
Five Family Fest
ANNUAL PARTY 2017



Camp Rainbow



Kris Kringle



Celebrating Heroes



Club Rainbow Family Retreat



Ride for Rainbows



Climb for Rainbows



Kris Kringle



Celebrating Heroes

Nur Jannah Binte Abdul Mutaleb
3 YEARS OLD

DIAGNOSIS:
Biliary Atresia



operation when she was just 45 days old, to remove a blocked bile duct and gall bladder and connect a section of her intestine directly to her liver.

Jannah's mother, Ida recounts, "After the diagnosis and later the Kasai operation, we prayed for a miracle to happen. We hinged high hopes that Jannah would get better because I kept blaming myself. The professor told me it was not my fault. But I still kept asking why. Everyone kept questioning me as well, including my parents, who said this had never happened in the family before."

Despite the surgery, Jannah's condition soon worsened and she was put on standby for a liver transplant. Ida continues, "We eagerly wanted to proceed but I was definitely not a possible donor because of our different blood groups. Jannah's father was a willing party but was found medically unsuitable due to dark spots on his lungs. Our extended families were unable to help either."

Biliary Atresia (BA) is a disease characterised by the absence or blockage of bile ducts, which normally drain bile from the liver to the intestines. An infant with BA needs to undergo a surgical procedure – a Kasai operation – as early as possible. This surgery aims to connect part of the intestine to the liver so that the flow of bile can be re-established.

Without surgery, about a third of the patients will not survive more than 18 months. With the Kasai operation, another third may survive early childhood, but could develop liver failure later, eventually requiring a liver transplant.

"Jannah means heaven. Nur means light. Nur Jannah's name means 'light from heaven'. She is our light from heaven".

Looking at Jannah now, one would never guess that this active and cheerful girl underwent two major operations before she even turned 1.

Diagnosed with Biliary Atresia when she was just a month old, little Jannah had a Kasai

"Jannah's bilirubin levels were dangerously high - about 500 µmol/L and there were no potential donors. We were desperate. Thankfully, at that point, a generous anonymous donor came forward and passed all the medical assessments."

The anonymous donor turned out to be Ida's distant relative. She had visited Jannah a couple of times previously and was moved by the family's plight. In a voice laced with gratitude, Ida relates, "I gave her a gift as token of our thanks but she did not want it. She said it was between her and God."

After the operation, Ida was faced with the difficulty of feeding Jannah. She says, "Jannah had been fed through the Nasogastric tube, a feeding tube that carries food or medication to the stomach through the nose, for almost 7-8 months since she was 5 months old. This meant that she had not been fed orally during this period. She did not know how to swallow. We had to see the dietician and therapist regularly. On the eve of Hari Raya in 2015, when she turned 1, the feeding tube was removed and we successfully managed to get her to drink from the milk bottle. Since Jannah already had teeth by the time she was one, she skipped eating soft foods like baby cereal and rice porridge, which most babies are started on from the time they are 6 months old.

“During this period, I am appreciative of the help that Club Rainbow has given us. Jannah has to see the doctor every month. The monthly financial assistance we receive helps with our transportation and diapers cost.

Ida, Jannah's mother





Diagnosed with Biliary Atresia when she was just a month old, little Jannah had a Kasai operation when she was just 45 days old, to remove a blocked bile duct and gall bladder and connect a section of her intestine directly to her liver.

She went straight to eating rice with finely minced vegetables and meat.”

To prevent Jannah’s body from rejecting her new liver, she has to take immunosuppressant medication, which lowers the body’s ability to reject a transplanted organ. However, one of the side effects of such medication is an increased chance of infections, especially in the early period after a transplant. Ida explains, “I have to be very cautious when it comes to hygiene and food preparation. After the transplant, Jannah has been admitted twice to test for liver rejection. Rejections can happen any time. When my husband comes home from work, he has to shower first before he can play with her. He sometimes complains that I am overdoing things but I tell him that it is all for Nur Jannah’s health. Cleanliness is the most important if we want to prevent Jannah from getting an infection. We do not go to crowded places. I have heard of some children with liver transplant rejections who have had to go through multiple transplants. I do not want this to happen to my Jannah.”

Ida continues, “During this period, I am appreciative of the help that Club Rainbow has given us. Jannah has to see the doctor every month. The monthly financial assistance we receive helps with our transportation and diapers cost. Our



social worker, Pauline, has also helped us so much. She is very nice and pleasant. She always makes time to call and visit us, either in the hospital or at our home. She will also inform us if there are any upcoming talks and seminars.”

“All the best to Club Rainbow on your 25th anniversary. May you continue to sustain the good work you do. Thank you for supporting us emotionally and financially.”

RECITAL OF HOPE

Lim Hong Xiang Samuel
18 YEARS OLD

DIAGNOSIS:
Acid Burn to Gastro-intestinal Tract

Tracheostomy* is a surgically created hole at the front of the neck and into the windpipe (trachea). A tracheostomy provides an air passage to help in breathing when the usual route for breathing is somehow obstructed or impaired.

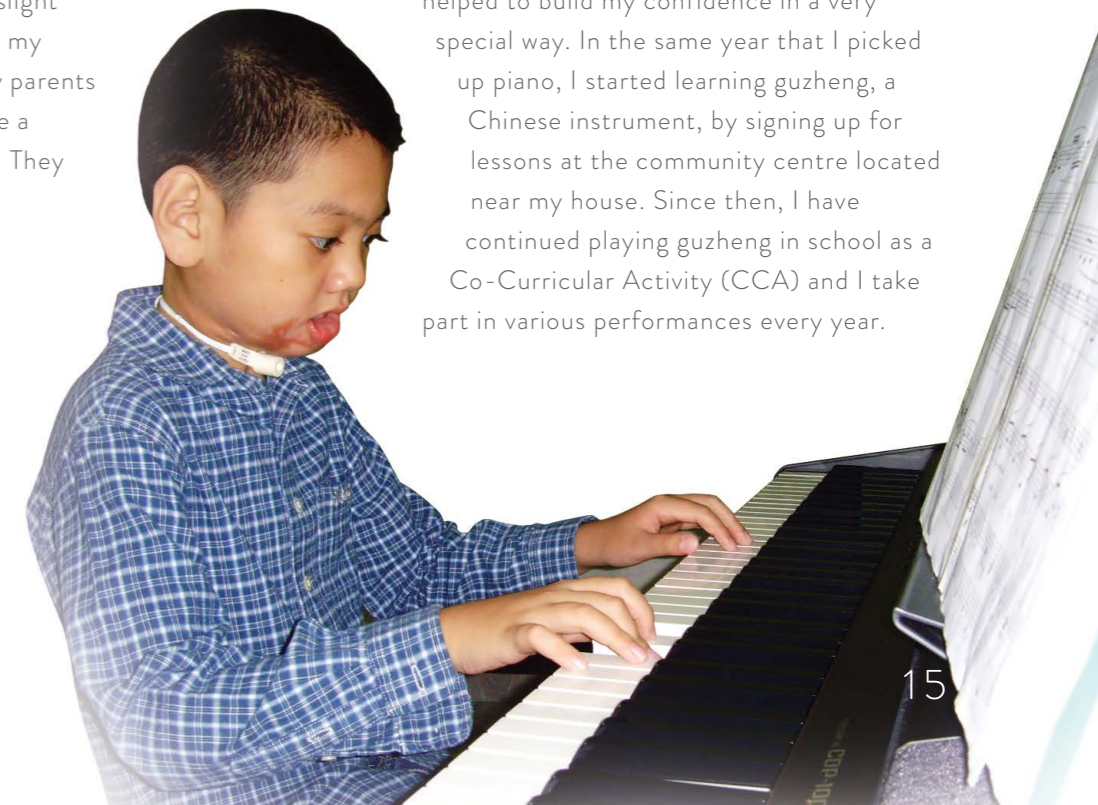
Gastrostomy^ is a surgical opening through the abdomen into the stomach. A feeding device is inserted through this opening, allowing the patient to be fed directly into their stomach, bypassing the mouth and throat.

My name is Lim Hong Xiang Samuel. I have speech impairment and I am unable to eat and drink like most people. When I was 3 months old, I was forced fed acid by one of my domestic helpers, which damaged my oesophagus and upper airway. I now breathe through a tracheostomy* and all of my feeds are through a gastrostomy^. I have had several episodes of intestinal obstructions due to the multiple abdominal surgeries I had in the past. Doctors have plans for a surgical reconstruction of my larynx and upper gastrointestinal tract in the near future.

Despite the slight difference in my physique, my parents raised me like a normal child. They

brought me everywhere when I was young, picked up sign language with me when I was 2 years old and enrolled me for piano lessons at the age of 7. They wanted me to socialise with other children very confidently.

I vividly remember my first Talent Development Fund (TDF) concert with Club Rainbow (Singapore) at 9 years old. I found my love on stage playing the piano and that performance motivated me to continue searching for new songs to practise and perform. I look forward every year to the TDF concert. Both the TDF and Education Awards presented by Club Rainbow have helped to build my confidence in a very special way. In the same year that I picked up piano, I started learning guzheng, a Chinese instrument, by signing up for lessons at the community centre located near my house. Since then, I have continued playing guzheng in school as a Co-Curricular Activity (CCA) and I take part in various performances every year.





Currently pursuing my Grade 8 assessment in piano and guzheng, my eventual goal is to obtain a diploma in both instruments. I am a Year 2 student studying in Nanyang Junior College and taking up a hybrid stream of H2 Chemistry, Mathematics, English Language and Linguistics and H1 Economics. It has been hard transitioning from Secondary school to Junior College. It is extremely demoralising and frustrating at times, especially when I have difficulty understanding certain topics and when I struggle to answer “supposedly” easy tutorial questions. There is also additional stress from peer competition and from repeatedly failing tests. To relieve some of the stress that is built up during school, I have joined my school’s guzheng ensemble.



“ Music has always succeeded in helping me convey my emotions, more so because I am unable to speak normally. It helps to dissipate any unhappiness I feel, calms me down and keeps me refreshed and centred.

My passion for music has brought me to appreciate the numerous lessons and practices I have because they help relax my mind and dispel my lethargy. Music has always succeeded in helping me convey my emotions, more so because I am unable to speak normally. It helps to dissipate any unhappiness I feel, calms me down and keeps me refreshed and centred.

Most importantly, my family and friends have been the pillars of my strength. They have encouraged me to survive and press on. Knowing that I can always fall back on my family and friends is always reassuring, because I know that they will always be standing behind me every step of the way, supporting me.



My passion for music has brought me to appreciate the numerous lessons and practices I have because they help relax my mind and dispel my lethargy.

I got to know some of my closest friends through Club Rainbow when we attended Camp Rainbow, an annual camp that I look forward to attending every year. Through the years of attending numerous camps, we have become inseparable. We often meet outside of camp to catch up and celebrate one another’s birthdays. Some of us are even willing to volunteer to help out in the camp despite our hectic schedules as we want to give back because we are grateful with what we have

Club Rainbow has helped me so much, and I would really like to express my thanks and gratitude. I wish that Club Rainbow will continue to lend a helping hand to other chronically ill children and impact their lives, just as it has left an imprint on mine. I would also like to congratulate Club Rainbow on its 25th anniversary milestone.

For all the children out there, just remember that there will always be light in the darkness; and a pretty rainbow after a storm, so don’t ever think of giving up!

A SON'S LOVE A MOTHER'S RESILIENCE

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Jonathan Tan Shao Em
18 YEARS OLD

DIAGNOSIS:
Chronic Asthma, Sleep Apnea,
Attention Deficit Disorder/Chest pains

Lucy is the loving mother & sole caretaker of Jonathan Tan Shao Em, a 18-year old robotic whiz-kid and soccer enthusiast.

Lucy and ex-husband separated shortly after Jonathan was born. She has since faced the struggles of motherhood alone, working part-time shift jobs to get them by. "I had a difficult time," she sighs. "Luckily, at that time, I had my family members to come in and help me look after Jonathan while I went to work."

Added to this burden was the discovery that her son suffers from Sleep Apnea - a condition that causes his blood oxygen levels to drop drastically. "When Jonathan was in Primary 3, his teacher would always call me to tell me that he falls asleep in class." Jonathan has since depended on a Continuous Positive Airway Pressure (CPAP) machine to help improve his attention at class. He is now a top performer in school, scoring the highest in Home Economics and placing 3rd at a regional science competition.

Sleep Apnea - a condition that causes Jonathan's blood oxygen levels to drop drastically.



Jonathan is now a top performer in school, scoring the highest in Home Economics and placing 3rd at a regional science competition.



"The CPAP is a small machine," Lucy elaborates, "It allows him to breathe in..." She pauses, musing over the the right words to articulate his case.

"Extra oxygen," Jonathan quips in, helpfully.

Quiet but thoughtful, Jonathan is one whose actions speak much louder than words. Lucy fondly recalls an incident where she had gone for an operation, two years back. "I never expected Jonathan to wait for me outside

the operation ward! He came down straight from school - I didn't call him. He took the effort. I was very surprised, very touched," she smiles, eyes brimmed with tears.

Mother and son share a strong and tender bond, though tenuous at times. She laments of an incident where her son had run away from home, leaving her deeply upset and stressed. "For Jonathan, I know he's not easy to bring up - I have to be more patient. It's hard for me also." Listening to music or

doing cross stitch have become welcome outlets for her to manage stress. If all else fails, Lucy knows that she can also readily depend on their Club Rainbow social worker, Grace, to lend a listening ear.

Motherhood is nevertheless a gift she has embraced wholeheartedly in spite of its difficulties. "As a mom, I do my duty to take care of Jonathan; from the time he was small to when he grows older. Make sure Jonathan goes down the right path, not the wrong path." She continues to lead him down the right path, rooting for his every achievement in school and ambitions to become a chef one day.



For Lucy, Club Rainbow has truly made a difference to both their lives. "I would like to thank Club Rainbow through the years that they have been helping me and Jonathan... I'm very happy to know Club Rainbow."

With the encouragement of her son and Club Rainbow (Singapore), Lucy has likewise found the strength to achieve her goals by pursuing English and Computer courses. "I decided to take these course because I went to Primary School only - now that I have the chance, why not?" She dreams of becoming an early childhood teacher in the future, and hopes to be able to volunteer at Club Rainbow events one day.

Club Rainbow has enabled Lucy and Jonathan to fulfill their dreams in more ways than one. In addition to food rations, Lucy expresses her gratitude for the financial assistance they have received in the past. "When I was jobless, I called up our first social worker, Cynthia, for help. They were really helpful. They were always there for me." Events organised such as an excursion to F1 and a short cruise present good opportunities for mother and son to bond, and play a part in the community. "When I graduate, I'd like to come back to volunteer at youth-based programs... I'd like to help people," Jonathan shares.

For Lucy, Club Rainbow has truly made a difference to both their lives. "I would like to thank Club Rainbow for helping me and Jonathan through the years. I'm very happy to know Club Rainbow."

“ I'd like to thank Club Rainbow, especially Cynthia, Allison, Pauline and Grace for motivating me and helping me a lot. Happy 25th Anniversary to all the staff!”

UNCONDITIONAL LOVE

Anisha Sonya
19 YEARS OLD

DIAGNOSIS:
Cerebral Palsy and Hypothyroidism

Anisha's mum, Sheila, recalled the birth of Anisha as being normal but baby Anisha's cries were very shrill. Upon tests, Anisha was diagnosed with hypothyroidism. She was in neo-natal intensive care for 10 days before being discharged. "Then out of the blue, when Anisha was about 3 months old, her entire left side from her left eye, left nasal, left part of her lips and her left limbs were in seizure for two days." From then began a long and painful struggle where Anisha was in and out of Intensive Care Unit (ICU) requiring long hospital stays. The darkest period was when Anisha was 4-5 years old, when she

spent more time in hospital than at home, typically "one week at home and three weeks in hospital." At the worst of her epilepsy, she suffered a seizure that lasted a month. After that episode, Anisha lost the ability to stand. It was heart breaking to see her only child going through such pain - many tubes inserted in her, being poked and pricked. As a single parent, it was particularly difficult for Sheila to care for Anisha. She had to earn a living by juggling jobs while relying on her mother to help care for Anisha. The first seven years was particularly strenuous on Sheila. When Anisha needed long hospital stays, she had to resign from her job. For two years, she was a full-time caregiver "until I nearly went mad."

Upon tests, Anisha was diagnosed with hypothyroidism. She was in neo-natal intensive care for 10 days before being discharged.

Then out of the blue, when Anisha was about 3 months old, her entire left side from her left eye, left nasal, left part of her lips and her left limbs were in seizure for two days. From then began a long and painful struggle where Anisha was in and out of Intensive Care Unit (ICU) requiring long hospital stays.





It took nearly 12 years to get her medication sorted out in terms of the type and dosage. “Although Anisha still gets tremors, her condition is now more stable. I now have a part-time job.” As Anisha is now older, a full-time helper is needed to help care for her especially to lift her.

When Anisha was diagnosed with epilepsy, the doctors and nurses tried to educate Sheila on the condition. She also did her

“ There is always sunshine at the end of the rainbow. If they are happy, then we are happy.

Sheila, Anisha’s mother

own research. “Only much later when I sent Anisha to Rainbow Centre that I learnt that it is Cerebral Palsy (CP). It was such a big word to me.” As a result of CP, Anisha had global development delay. Her bones are also soft. She is unable to speak and is wheelchair bound. “Now we are able to tell from her facial expressions and the sounds she makes on what she needs.” Caring for Anisha is like caring for a baby trapped in a 19-year-old body - feed according to

schedule and changing her diapers. Every six months she still needs to go for blood tests to monitor her hypothyroid condition. “I thank God that we have come this far. When I see other children with more serious illness such as Kawasaki disease, I think Anisha is ok. Through this journey, I have learnt to be patient and to love unconditionally.” Sheila’s hope for the future, “I wish there is a centre or place that can care for special needs adults when their parents pass away.”

“When Anisha was 4 years old, we were approached by Club Rainbow (Singapore) and I appreciate the transport provided by Uncle John in fetching Anisha to her medical appointments and the various events. We also receive food rations. Any help is welcome.” At Club Rainbow, we get to know other parents with children suffering from chronic illnesses and there is a sense of inclusion.” Sheila recalled, “One of my most memorable time was the cruise to Malacca. Despite being in wheelchair, the logistics and arrangement were made for us to actually go around Malacca. I would not have been able to make such a trip on my own.” What touched Sheila was that “Club Rainbow came to me, instead of me approaching them.” She also found the workshops organised by Club Rainbow useful. “There were times when you are with your sick child and faced



with unending bills to pay, you feel like you are up to your neck. The social worker always gives me a listening ear, so that I don’t feel trapped within four walls.” To help ease the physical strain of lifting Anisha, Sheila is also very grateful for the hoist that was recently purchased under subsidy.

Lastly, Sheila expressed her gratitude to Club Rainbow, “Thank you so much for the tremendous support for so many years. Any form of help that you give and the awareness you create is good.”

Sheila has this to share with other parents of special needs children, “There is always sunshine at the end of the rainbow. If they are happy, then we are happy.”

At Club Rainbow, we get to know other parents with children suffering from chronic illnesses and there is a sense of inclusion.” Sheila recalled, “One of my most memorable time was the cruise to Malacca. Despite being in wheelchair, the logistics and arrangement were made for us to actually go around Malacca. I would not have been able to make such a trip on my own.” What touched Sheila was that “Club Rainbow came to me, instead of me approaching them.”

SOLDIERING ON AS BROTHERS

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Andy Soh Hung Zheng 16 YEARS OLD

DIAGNOSIS:
Global Development Delay;
Severe Pes Planus

Andrew Soh Hong Yi 11 YEARS OLD

DIAGNOSIS:
Chronic Eczema, Allergic Rhinitis

Global Developmental Delay (GDD) is the general term used to describe a condition that occurs during the developmental period of a child between birth and 18 years. It is usually defined by the child being diagnosed with having a lower intellectual functioning than what is perceived as 'normal'. It is usually accompanied by having significant limitations in communication.

As the firstborn in the family, Andy's parents waited excitedly for his arrival 16 years ago. They held high hopes and aspirations for him.

Yet the first sign of trouble came when Andy was 2 months old and he refused to drink his milk. At first Andy's parents thought it was because the milk was unsuitable, so they tried out other milk formulas. However, Andy's condition did not improve over time. At 11 months old, Andy weighed about 6 to 7 kg as compared to the 8 to 10 kg that other 11-month-old babies would normally weigh. Doctors later diagnosed Andy with Global Developmental Delay.



Andy's childhood was marred by frequent doctor and hospital visits. He often suffered from frequent bouts of fever and was also warded in the hospital multiple times for lung infection and hernia. It pained Andy's parents to see their child getting sick so frequently. They were often at a loss as to what they could do to help Andy and how to make him feel better. There came a point during one of Andy's hospital stays where Andy could no longer eat and drink, and had to be put on intravenous drip to ensure he was still getting the essential nutrients and fluids. Thankfully, he recovered.

Andy's family will be able to attest to the many challenges he has had to face both physically as well as mentally. Andy cannot speak or communicate his thoughts and wants well. He walks with an unsteady gait and has difficulty balancing himself. This means he is prone to falls. He experiences weakness in his limbs, and has had surgery for his dislocated elbow (which he sustained in a fall) and severe pes planus, which is more commonly known as flat feet.

Andy usually requires the aid of a wheelchair and wears ankle-foot orthosis to support his legs. With much difficulty, Andy has learnt to navigate around his school compounds, MINDS - Woodlands Garden School and is able to put on his clothes by himself, but is not able to do much else on his own. Andy's inability to take care of himself remains a constant concern for Andy's mother, Madam Lee Siok Eng, who often ponders what the future holds for him.

Despite the myriad of challenges that life has thrown at them, Madam Lee concedes that she still feels blessed because she has a younger son, Andrew, who helps her out at home. Even at the young age of 11 years old, Andrew is happy to share the responsibility of caring for his older brother. She also feels blessed to have had the support of Club Rainbow (Singapore) since 2014, when Andy first joined the organisation as a beneficiary.

Andy uttered his first word to his family after being placed in Club Rainbow's art therapy programme in 2015. This has been very encouraging for Andy's family who for years had hoped that Andy would be able to communicate to them. Andy is scheduled



Madam Lee likens her experience with Club Rainbow to being part of a big family. She has found it helpful to hear from other parents about their experiences, to exchange tips and to provide each other with support.

to start speech therapy organised by Club Rainbow and Madam Lee is hopeful that Andy will be able to speak more in time to come.

Andy has also benefited from Club Rainbow's transport services to enable him to turn up for his medical appointments and other activities planned by Club Rainbow. Andy's parents also appreciate that the activities organised by Club Rainbow are specially planned with the needs of children like Andy in mind. Andrew was also allowed to attend some of the programmes and enjoyed himself so much that he started badgering Madam Lee to let him join Club Rainbow as well. With a wry smile, Madam Lee reveals that in the later part of 2015, Andrew finally joined Club Rainbow as a beneficiary when a routine visit to the doctor for a stomachache led to the discovery that Andrew suffered from chronic eczema and allergic rhinitis.



Even at the young age of 11 years old, Andrew is happy to share the responsibility of caring for his older brother.



Madam Lee likens her experience with Club Rainbow to being part of a big family. She has found it helpful to hear from other parents about their experiences, to exchange tips and to provide each other with support. It is also a plus point for her that Andrew is now able to participate in Club Rainbow activities too. Both brothers have found a safe haven in Club Rainbow, where they are able to have fun alongside one another.

On its 25th anniversary, it is the sincere hope of Madam Lee that more children like Andy will be able to benefit from Club Rainbow's services and programmes.

CONQUERING ALL WITH HOPE

Danish Hilman Bin Zakaria
10 YEARS OLD

DIAGNOSIS:
Nephrotic Syndrome

An adorable and bubbly child, Danish loves fast food and harbors dreams of being a footballer when he grows up. But his cheerful demeanor belies the fact that he is suffering from a combination of medical symptoms which causes kidney damage.

At the age of 3, Danish was diagnosed with the disease when he suddenly became bloated and developed a fever and flu, and had to be admitted to KK Women's and Children's Hospital (KKH).

His mother, Norleza, found it hard to come to terms with the news at first. "My eldest son, Lutfir, has chronic pancreatitis. It wouldn't have been so bad if it was only one child. I

felt down because two of my children have chronic illnesses," she says matter-of-factly. Thankfully, her daughters are healthy.

Because of his low immunity, Danish is prone to catching ailments and often misses classes. He has to take oral corticosteroids regularly, leading to weight gain. Each dosage is monitored carefully by Norleza.

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Because of his low immunity, Danish is prone to catching ailments and often misses classes. He has to take oral corticosteroids regularly, leading to weight gain.



“To children who are in the same boat as me, be patient and ignore the mean things others say. A big thank you to Mummy who loves me very much. And for giving me food!”

She elaborates, “If I administer the minimal dose of 5mg, Danish will experience water retention and lose a lot of albumin in his urine. He then needs to go to the hospital to flush out the excess fluid and replenish albumin in his body. There was a period of time when he was admitted to hospital almost every month because I wasn’t sure of the proper dosage. For the past six years, I have been checking his protein levels via the urine dipstick test every day.” “As corticosteroids can hinder height development, I also have to monitor Danish’s growth using the growth chart. We are praying hard for him to recover,” she adds.

Norleza, who quit her previous job to look after her sons, slipped into depression after her husband abandoned the family, but encouragement from her mother, sister and friends gave her the strength to carry on.

Determined to care for her four children to the best of her ability, she is now diligently searching for a job. “This experience has made me more resilient,” she asserts. “Even



though it’s just me and my kids now, as long as I have them by my side, I feel contented. I want them to lead a better life. I’m willing to work hard to make it come true.”

Norleza first came to know of Club Rainbow (Singapore) when Dr Perry Lau, Lutfir’s doctor, told her about it. She credits Club Rainbow for making a major difference in her life: “We have benefitted greatly from Club Rainbow’s food rations and vouchers.”

Besides helping with finances, the organisation also offered emotional and informational support. Norleza is grateful for the counselors who listened to and guided her.

“Recently, I also attended a talk organised by Club Rainbow on managing chronic liver disorder, conducted by Prof Quek Seng Hock. It was a good opportunity to learn more about the illness and clear my doubts,” she says. “I really appreciate everything that Club Rainbow has done - no words can describe my gratitude.”

Despite his condition, Danish is doing remarkably well in school. Besides being



Despite his condition, Danish is doing remarkably well in school. Besides being a prefect and science monitor, he was also chosen to be a buddy tutor and help his classmates with their homework. His excellent academic performance is an impressive feat given that he does not have tuition or remedial classes.

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When asked about obstacles that his illness has caused, Danish rattles off quite a few. “I love soccer but cannot choose it as my CCA because the school didn’t allow me to. I was also prepared to score well in my mid-term exams but on the day of my English and Malay papers, I didn’t feel well and had to go to the hospital. So I couldn’t sit for them. I’m disappointed because I am good in those subjects.”

He continues, “Some students will call me names like ‘handicapped’ and make me angry. I do not listen to them. To children who are in the same boat as me, be patient and ignore the mean things others say.”

Does Danish have anything else to add?

“A big thank you to Mummy who loves me very much. And for giving me food!”

SWIMMING BEYOND LIMITATIONS

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Jeremiah Liauw
11 YEARS OLD

DIAGNOSIS:
Spina Bifida

Jeremiah was born with myelomeningocele- the most serious type of spina bifida- and had to be whisked to the neonatal intensive care unit. He had an operation that same fateful day to close the opening in his back, which caused part of his spinal cord and nerves to be damaged.

Following the natural delivery of her second son at Mount Alvernia Hospital in 2006, Mrs Michele Liauw sensed something was amiss when the nurse did not place the baby on her chest.

She later learnt that baby Jeremiah was born with myelomeningocele - the most serious type of spina bifida - and had to be whisked to the neonatal intensive care unit. He had an operation that same fateful day to close the opening in his back, which caused part of his spinal cord and nerves to be damaged.

Mrs Liauw, recalled: "He stopped breathing a few times after the operation, so we decided not to move him to another hospital."



She breastfed him in the hospital, where he was warded for 18 days. On his eighth day of birth, he had to undergo another operation when doctors detected that his spinal fluid was not flowing properly, she said.

She remembers vividly that the neurosurgeon encouraged her by likening Jeremiah to "a torn pair of jeans that required someone's help to patch back".

Mrs Liauw was not shy to admit that she did not always heed the doctor's advice and relied on her faith to get through each hurdle in Jeremiah's life instead.



“ I just like swimming. I can do somersaults and backflips in the water. I can also move faster in water than on land.

When there was a buildup of fluid inside his skull, known medically as hydrocephalus, she chose not to put him through surgery to insert a shunt to drain the excess fluid. She also could not bear to put her child under general anesthesia once every three months to complete the MRI scans ordered by the doctor.

Mrs Liauw attended courses to learn how to help her son. From the time he turned 8 months old, she got him to do commando crawls to build his upper body strength and compensate for the weakness in his legs.

Jeremiah also lacks bladder control due to his spinal cord problem. During his third day of school in 2015, he accidentally wet himself when his diapers were not placed properly. Mrs Liauw was impressed when she learnt that his 9-year-old classmates helped to clean his seat in the classroom without a word of complaint.



Jeremiah has asked his parents why he is born that way although they are both normal and healthy. Mrs Liauw's reply to him was: "Everything happens for a reason, but we don't always have the answers. Maybe you are born this way to be an inspiration to others. Just remember to keep on trying and not give up."

She is also grateful that Jeremiah's principal set aside a space in the general office of St Joseph's Institution Junior for him to perform clean intermittent self-catheterization - a procedure to help him empty his bladder of urine.

These days, 11-year-old Jeremiah is making a splash in para-swim meets. In early August 2016, he won medals in the Singapore National Games and Singapore National Para Games. Later that same month, he won three gold medals at the Singapore Press Holdings Foundation Para-Swimming Championships.

Swimming in the S4 classification for the men's Division B (ages 10 to 12), he won all three of his events- 50m freestyle, 50m breaststroke and 50m butterfly- and clocked personal bests in his freestyle and breaststroke events.

When Jeremiah was asked why he likes swimming, he said: "I just like it. I can do somersaults and backflips in the water. I can also move faster in water than on land." Jeremiah gets around his house by using elbow crutches and uses a wheelchair when he is outdoors.

Jeremiah is also musically inclined. He plays the cymbals in his school's brass band and took up lessons to learn how to play the

ukulele with Club Rainbow in 2016. He also recalls dancing to his heart's content in a large hall during Disco Night of Camp Rainbow 2015.

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A FAMILY'S BATTLE

Mohamed Sayed Sameer Bin Abdul Kadir 15 YEARS OLD

DIAGNOSIS:
Grade 5 Vesicoureteral Reflux

Since he was born, Mohamed Sayed Sameer Bin Abdul Kadir has been in and out of the hospital countless times. However, this has not interfered with his love of outdoor sports like soccer, basketball and shooting.

The active boy, who is in National Police Cadet Corps (NPCC) and intends to be a police officer, says, "My friends don't treat me any differently and I've been managing school, supplementary classes and weekly Saturday tuition lessons quite well."

Sameer was initially given monthly IV antibiotic injections, but as time went by his body rejected the drugs. He then underwent two operations when he was 8 months old and 13 months old respectively. Although a scope revealed that everything was in order, he developed asthma two years ago and has since been taking medication for it.

He visits the hospital for a check-up once every six months, which will end when he is 18 and ready to enroll in National Service.

As one of Sameer's kidneys is gradually shrinking, he has to take extra precaution by cutting down on cold drinks, watching his diet and avoiding smoking and drinking.

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For nine years, Sameer has been attending Camp Rainbow and other Club Rainbow activities, and is reluctant to miss any. Having interacted with others who also have chronic illnesses, he is keen to become a Club Rainbow volunteer in the future. In his own words, he wants people to “go ahead and do your best. Never stop trying because you only get one life.”

His mother, Lujahhan, is proud of him. “Sameer is a happy-go-lucky and carefree child. He helps with the household chores and knows how to comfort me when I’m not in a good mood.” She says in relief, “The doctor mentioned his growth might be affected, but he turned out the tallest in the family.”

Lujahhan, who has been working as a receptionist in the customer service sector for eight years, recently became the sole breadwinner after her husband lost his job. She persevered even when facing hardships during her first few months at work, and today she has solid rapport with many customers. “They were curious to know how I can still smile at work. It’s because I keep my work and personal life separate. This trial has strengthened me,” Lujahhan explains.

“My friends don’t treat me any differently and I’ve been managing school, supplementary classes and weekly Saturday tuition lessons quite well.”

But keeping a positive mindset didn’t come easy. She struggles to control her emotions as she recalls the helplessness she felt during the early days of Sameer’s diagnosis. “I was so worried that I forgot I was in confinement and accompanied him to the hospital. The doctor said the disease might be brain-related and my mind went blank when I heard that. When his condition was eventually identified, I was relieved and sad at the same time. I kept asking God, why me?”

The cold treatment from her own relatives made it worse. “They made negative comments about him because they don’t understand his condition. People actually tried to dissuade us from going ahead with the operations, but we are his parents and the choice was ours. We did the right thing.”

As the topic turns to the support she has received, Lujahhan is full of praise for the doctors, nurses and social workers who have each helped the family in their own way. She is also appreciative of Club Rainbow’s efforts in easing the financial burden by dispensing food rations and diapers when Sameer was younger.

She says, “Prof Yap Hui Kim, Sameer’s doctor, was the one who referred us to Club Rainbow. Thanks to the organisation, we were able to travel to Kuala Lumpur as a family for



Lujahhan’s greatest wish now is for her three children to stay healthy, and for Sameer’s condition to improve.

the first time with all expenses paid. During the trip we bonded with other families; I could relate to them as we have all been through difficult times. Seeing how they overcame their own problems truly inspired me.”

Her greatest wish now is for her three children to stay healthy, and for Sameer’s condition to improve.

“I need to be strong for all of my kids. It is challenging but I can stand on my own two feet now and I want to do it without solely depending on others for help,” she declares confidently. “Although there have been ups and downs, we made it through together. My children are always there for me and they taught me to never give up in life.”



LITTLE DRUMMER GIRL

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

**Chieng Zhi Wei,
Anastasia Mary**
13 YEARS OLD

DIAGNOSIS:
Post-Op Transposition of the Great Arteries (TGA)/Eacral and Palsy with Recurrent Laryngeal/Hearing Impairment

Within 6 days from birth, little Stasia had to undergo major open heart surgery (OHS) for her heart condition. It was only later, after her surgery and discharge from hospital when Anastasia was also found to suffer from profound hearing loss in her right ear. When she turned 8 years old, Anastasia had to undergo yet another operation to remove the pacing wire that had been embedded during OHS as it was causing skin irritation.

Youngest in the family, Anastasia is studying in St. Anthony's Canossian Secondary School. She likes going to school and her favourite subject is Science. The bubbly and cheerful girl sat for her Primary School Leaving Examinations (PSLE) in September 2016. In preparation for the exams, she has been attending Club Rainbow (Singapore)'s weekly Saturday tuition on a regular basis.

Despite being hearing impaired in one ear, Anastasia enjoys playing the electone and especially the drums. She dreams of becoming a professional drummer who can showcase her talents on a bigger stage one

day. In fact, young Anastasia has already chalked up a number of public performances at some of events organised by Club Rainbow.

"When I get nervous, I look for Mummy and I don't feel so scared anymore," says Anastasia with a big smile. When asked to provide her fellow Club Rainbow peers with advice on how they could reduce performance jitters, she simply replies, "You just need to practise." Anastasia will be taking her Grade 3 theory examinations for the drums at the end of 2016.



“When I get nervous, I look for Mummy and I don't feel so scared anymore,” says Anastasia with a big smile. When asked to provide her fellow Club Rainbow peers with advice on how they could reduce performance jitters, she simply replies, “You just need to practise.”

Anastasia is one of the recipients of Club Rainbow's Talent Development Fund (TDF) Award in both 2013 and 2014 which helps defray the cost of her electone and drum lessons. She started learning how to play the drums in 2014.

The close-knit family may joke around and laugh a lot on the exterior, but they have their own share of difficulties as well. “When Stasia was born, nobody – not even my husband – would tell me about her condition,” recalls Anastasia's mother, Veronica, her eyes inevitably filling up with tears at the memory.

“I was diabetic – they (my family) were worried that I would not be able to handle the news. My blood pressure spiked when I eventually found out about it.”

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Looking at the highly active and energetic girl today, one would never guess that Anastasia has a heart condition. In her early years, Stasia was unable to participate in sports with peers of her age. She was also easily prone to infections. “Back then, we had to ask for antibiotics – even for a trip to the dentist,” added her mum.

When asked how life has changed since Anastasia was born, Veronica explains, “After joining Club Rainbow, I realised that there are many others out there who are in much more need of help than we are. Meeting these people allowed me to treasure what I have; I began to appreciate those around me more.”

“The hardest part of this journey was seeing little Stasia, who was just a tiny baby, going into the operating theatre. She was so young, just a few days old, yet she had to undergo those intrusive procedures. Right now, all I hope for is for her to meet someone nice who would be able to take care of her in the future.”

Veronica relates that she first found out about Club Rainbow when Anastasia was 3 years old in 2007, when Club Rainbow held an event at Compass Point Mall. Since then, Anastasia has participated in many of



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the programmes organised by Club Rainbow including the Annual Party and Ride for Rainbows as well as in many workshops such as Robotics, Printmaking and Creative-writing.

Veronica encourages other parents who may be facing similar situations to accompany their child to participate and try out new activities with Club Rainbow. “It’s okay if you are unable to join in the activities – you can still make some new friends, and your child can meet new people too.”

“I hope that Club Rainbow can reach out to more families in need of help, and let them know that they are not alone.”

I CAN MAKE A DIFFERENCE

Muhammad Azrin Bin Ali
28 YEARS OLD

DIAGNOSIS:
Thalassaemia Major

Azrin comes from a family of five and is the eldest of three children. He is an ex-beneficiary of Club Rainbow (Singapore) (CRS), having graduated seven years ago. His younger brother, Azuan is also an ex-beneficiary of Club Rainbow. Both brothers suffer from the same blood disorder, Thalassaemia Major. Azrin’s condition was pre-diagnosed during his mother’s pregnancy. His mother is a carrier and his father is a Thalassaemia Minor.

From the age of 1, Azrin needed blood transfusions every six months which increased to every four months by the time he turned 6, then to every two months when he was 12. The frequency of blood transfusions increased with his physical development. As an adult, he now needs blood transfusion every four weeks. In addition to the frequent blood transfusions, he also needs to do a monthly iron detoxification procedure at home. Juggling work commitment while self-medicating as well as the countless hospital visits has proved to be extremely challenging for Azrin.

Up until when Azrin’s parents were introduced to Club Rainbow (Singapore), they went through a very depressing and difficult time, especially for his mother who faced rejection by family members. Arrangement was made to provide financial assistance for Azrin’s family to help them alleviate expenses on medication and education as well as to provide food rations and emotional support which helped to overcome their struggles.

Azrin maintains a bright and positive outlook and does not let his condition get in the way of fulfilling his talent and paying forward by helping others. With the help of Club Rainbow, he received a grant from the Talent Development Fund to purchase his drums and learnt drumming.



He is now an accomplished and certified percussion player. Azrin has since taught percussion to disadvantaged children at Darul Ma'wah (Jamiyah Children's Home). While Azrin and his band busk in their free time, he is also an active soccer player with the X League on Sundays. Azrin summed up his outlook, "I still have a heart and brain. I do and think what is right. I can still make a difference."

In 2005, the enthusiastic Azrin pioneered the first batch of youth volunteer committee members when he had "outgrown the camp" which was meant for those below age 17.



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The annual flagship Club Rainbow event made a big difference to the young Azrin. It was something he looked forward to every year ever since he joined Club Rainbow. "I missed out on all the school camps as the teachers did not want to be held responsible because of my medical condition." Camp Sunshine (as it was then called) at that time also included beneficiaries from Children Cancer Foundation. It was a big three-day event held in June, attended by 200-300 children, befrienders, volunteers and organisers. "I used to think that Club Rainbow paid for the various services to get the camp organised. It was an eye opener when I realised the 6-8 months' effort was all put in by teams of volunteers, with many nights of planning to make the camp such a memorable experience for the children." Azrin was so inspired by the dedication of these volunteers that he decided to join them even after he had graduated from Club Rainbow. "I wanted to give back as I have received so much."

In 2015, Azrin was nominated by the Club Rainbow (Singapore)'s Council Members to be the Chairman of the Committee for



Camp Rainbow. He rose up to the challenge and successfully managed the event well within a tight budget. His biggest challenge was in getting sponsorships for the event. "As a result of that role, I have built my confidence and self-esteem. I am now more outspoken and I've learnt time management." In fact, the theme for the camp was aptly named, "Where Got Time?" Managing a committee of 50 members was also no mean feat for the young man.

Sylvia Mak, Club Rainbow's social worker who was assigned to Azrin since he was 5, said with great pride, "He was an active camper and responsible volunteer who is well-respected by others. We had feedback that Azrin has good follow-up." Sylvia who has seen Azrin

“I wanted to give back as I have received so much.”

grow up from a young child, to a teenager and to an adult added, "Azrin is an active contributor to society. He shows resilience despite his challenges. He is a good role model for Azuan. I am very proud of him."

It wasn't just the camp that made an impression on Azrin. He was especially touched by his committed Club Rainbow befrienders. "My parents were very strict with us. Going to the camp came with conditions. I had to earn all my trips to every Camp Rainbow by doing well in my exams. When I was in Primary 4, I failed by a few marks and my mum withdrew my registration but separately, private arrangement was made with my befriender that I could go... at the last minute." He remembered his two befrienders fondly. "Every year, we had the same befriender. There were two, a banker and a pilot whom I kept in touch for years. They visited us at home and the pilot gave me Math tuition after my camp for the rest of the year. This was despite his busy flying schedule. He drove me to Pasir Ris Park, just to give me a break from my home environment. And I passed my final exam. He went beyond being just a befriender."

Lastly, a grateful Azrin who benefited from Club Rainbow in more ways than one - as a beneficiary and volunteer, extend his good wishes, "Congratulations to Club Rainbow for helping so many children in the last 25 years. Continue with your current motto. I look forward to your 30th anniversary."

DEFYING THE ODDS

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Chan Ka Ho
6 YEARS OLD

DIAGNOSIS:
Cerebral Palsy

“After the operation, he was so swollen... He was taking so much medication. It hurts to see him go through all that,” recalls Mrs Chan.

“I felt devastated, I would say. It was only three days after he was born - it was really scary. The risks involved for the operation were high for an infant,” adds Mr Chan. “It was after that he fell very sick. The doctors couldn’t really guarantee that he’d be able to pull through - we were told to prepare for the worst.” Further

complications with his oxygen supply would later lead to the development of air bubbles in his brain, subsequently resulting in Cerebral Palsy.

Six years have since gone by, and Ka Ho has grown to become an animated and happy boy. “He’s always been cheerful. As he’s grown older, he’s become a little more disobedient though - he knows how to talk back,” laughs Mr Chan. “He likes people. He’s really happy when there are a lot of people who come by to visit.”

At just 26 weeks of gestation, Ka Ho was born premature to loving parents Mr and Mrs Chan. As his air passageways were underdeveloped, blood and bodily fluids flowed uncontrollably into his lungs, jeopardising his ability to breathe. With his life hanging in the balance, doctors had no choice but to operate on him immediately in order to save his life.



Ka Ho also loves to sing. “He likes watching videos on YouTube of singing competitions,” smiles Mrs Chan. Upon being prompted to showcase his singing abilities, Ka Ho grins and giggles sheepishly, much to the amusement of his parents.

Mr Chan motions to the colorful cast covering Ka Ho’s legs. “He still can’t walk. There’s a vein in his legs that’s very tight which causes his legs to cross involuntarily.

“The doctor’s quite optimistic about it, the physiotherapist is as well. Generally, he knows how to walk; it’s just that he’s not able to balance himself for now. His veins are too tight, but he knows the momentum; his motor skills are there.

Mr Chan, on Ka Ho’s ability to walk in the future

He went through a recent operation to cut the vein. His right hipbone is also jutting out a bit too much, because he doesn't exercise his legs - he'll have to undergo another procedure to put it back into the right position." Coupled with consultations with a physiotherapist, his parents remain hopeful of his ability to walk on his own in the future. For now, Ka Ho remains highly dependent on Mrs Chan to accompany him to the Cerebral Palsy Alliance Singapore (CPAS) school for lessons.

For Mr Chan, the entire experience has broadened his perspective on children with disabilities in Singapore. "I feel that I am more accepting towards other children with special needs; I really do understand why the kids are behaving in such a manner, and what the parents may be feeling. It's definitely not easy," shares Mr Chan.

"One of the most challenging things is the lack of awareness. When I share my experience with my friends, they don't really understand; they question and speculate. It's only when they visit do they understand. I'm not sure what you can do about awareness though - even for me, there's a difference between 'coming across' these things and experiencing them for yourself."

Ultimately, both parents remain thankful for organisations such as Club Rainbow (Singapore), which continue to provide



5 years have since gone by, and Ka Ho has grown to become an animated and happy boy. "He's always been cheerful. As he's grown older, he's become a little more disobedient though - he knows how to talk back," laughs Mr Chan. "He likes people. He's really happy when there are a lot of people who come by to visit."

invaluable support to the healthy development and growth of their son.

"I've learnt a lot from the other parents that we meet," mentions Mrs Chan. "It's easy to exchange information about our kids and share our experiences." adds Mr Chan, "When you meet up with parents sharing the same situation, it's also another platform to distress and find someone to talk to - you don't need a solution, you just need someone to talk to." The family makes sure to attend social programmes like the Straits Construction Dinner & Dance and the Royal Caribbean Cruise for Ka Ho to relax and enjoy himself.

For both parents, their hopes for the future lie solely in the full health of their only son. Smiles Mr Chan, "I hope he grows up healthy and happy; to be independent, and to take care of his own basic needs. That's our wish."

PILLAR OF SUPPORT

Goh Jia Yun
18 YEARS OLD

DIAGNOSIS:
Down Syndrome & Heart Condition

"We just received Jia Yun's Piano Grade 1 Certificate yesterday!" enthused Jia Yun's mother, Madam Loo Fong Kiew, as she showed us the comments given by the examiner. "I was so worried because her teacher said she was not ready, but I just felt like we had to give it a try and I am glad we did."

And she is completely deserving of the award. "I decided that I wanted Jia Yun to live like any other children of her age. I wanted her to study in a mainstream primary school, like everyone else." To make it happen, Madam Loo made personal visits to many primary schools to try and gain admission.

In fact, Jia Yun has performed on the piano at various Club Rainbow (Singapore) events like the Annual Party in 2016. She has been learning to play the piano since 2010 and her piano school fees are offset using the Talent Development Fund (TDF) awarded by Club Rainbow.

Madam Loo, has played a huge part in her life. In 2015, she received the Exemplary Caregivers' Award by Club Rainbow (Singapore). "I do not expect any rewards for bringing Jia Yun up, I am only trying to give her whatever I can provide her with. I want her to have a normal childhood," says Madam Loo. "Nevertheless, this award holds a special meaning in my heart as it encourages and gives me the strength to continue this journey. It makes me feel that everything I have done for the past 18 years has been worthwhile."

Children with Down Syndrome typically have smaller statures, and the cheery, ever-smiling Jia Yun is no exception. As compared to other kids, children with Down Syndrome do everything a bit later on the development charts - they need to put in a little more effort, a little more time to achieve what peers of the same age can. However, it is exactly because of this that makes every milestone a cause for celebration, which is why Jia Yun's mother was beaming with pride during the interview.



Her efforts paid off when Madam Loo managed to convince the principal of Unity Primary School to take Jia Yun in as a student. Worried for her daughter's performance and ability to cope in school, Madam Loo decided to attend classes with Jia Yun every day for the next six years from the time Jia Yun was 7 to 12 years old.

"We learnt together, and studied together," she chipped in. Many people asked me, "Aren't you tired?" And I would reply, "I count my blessings everyday. As long as I have the energy to walk, I will walk with her all the way. I don't ask for any reward; I only wish that she will grow up as a happy child."

However, she admitted that she was worried about Jia Yun's future. Fortunately, Jia Yun has two elder brothers who dote on her dearly. The close-knit family just visited KidZania at Sentosa in June 2016. "The activities there looked so fun, her elder brother asked if he could join in!" Jia Yun's mother said with a laugh as she recalled the outing, which was organised by Club Rainbow.

The mother and daughter duo recall many memorable moments at Club Rainbow, which is not surprising since they are regulars at many Club Rainbow events.

“ Jia Yun loves the activities at Club Rainbow, and I am really thankful to Club Rainbow for all it has done for us the past few years. She is especially interested in photography – I never knew that she could take photographs so well if not for the photography workshops held by Club Rainbow.

Jia Yun's mother



"Jia Yun loves the activities at Club Rainbow, and I am really thankful to Club Rainbow for all that was done for us the past few years. She is especially interested in photography – I never knew that she could take photographs so well if not for the photography workshops organised by Club Rainbow."

When asked if she had any wishes for Club Rainbow on her 25th anniversary, Jia Yun responded by drawing a birthday card, filled with many stickers of Hello Kitty, her favourite cartoon character.



Jia Yun has performed on the piano at various Club Rainbow events like the Annual Party in 2016. She has been learning to play the piano since 2010 and her piano school fees are offset using the Talent Development Fund (TDF) awarded by Club Rainbow (Singapore).



FROM HEART PATIENT TO ASPIRING DOCTOR

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

S. Hema Viganeshwari
20 YEARS OLD

DIAGNOSIS:
Atrial Septal Defect (ASD)/
Large Secundum

Hema said that though the surgery was a success, her heart remained enlarged over the next few years. It meant that the Bharatanatyam dancer had to stop dancing for a year and put her diploma course at the Singapore Indian Fine Arts Centre on hold.

Hema, now 20, relishes in role-playing in Bharatanatyam, an Indian classical dance originating from Tamil Nadu. She said: "I can be an ardent devotee in one song and

an angry spouse in another. I take the audience to different worlds, though they may not all understand the language of the accompanying music."

It was a long road to recovery. Hema recalled: "My exhaustion and inability to catch up with others once I was able to go back to my classes put my condition in perspective for me. These challenges only lasted a year and while I still have to go for annual check-ups, I count myself lucky that my condition was discovered early and treatable."

She had to give herself time to resume her active lifestyle. This was because she got tired easily during dance classes. Hema reveals that she initially relied on her classmates to carry her schoolbag and had to turn to them for support when navigating stairs around the school.

For two years, Hema endured chest pain whenever she did strenuous exercise. When a doctor picked up a heart murmur and sent her for further tests, she was diagnosed with atrial septal defect at the age of 9. By the time she was 10 years old, she had undergone an open heart surgery to close the hole in the wall between the two upper heart chambers.



“ Club Rainbow made me realize that Bharatanatyam is an art form that can be appreciated by everyone. I would be honoured to return to Club Rainbow one day to teach dance or give tuition.

Hema is now actively pursuing her twin passions of dance and medicine. She has started her first semester at the National University of Singapore's Yong Loo Lin School of Medicine and is convinced that being a doctor allows her to contribute back to society.

Since young, she has heard countless stories of her parents' experiences working in the healthcare sector. Her mother is a nurse while her father used to be a paramedic. Besides being inspired by them, she is also grateful for their support. She relates, "Following my surgery, they helped me to kick start my dance classes, scheduled extra dance classes for me, took time off their busy schedules to accompany me to and fro classes and even arranged performances for me to hone my craft."



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Considering every Club Rainbow (Singapore) event she has attended as “fun and meaningful”, Hema counts a Bangkok trip with Club Rainbow as one of the most memorable ones.

Hema lives by the philosophy of “Never give up”. She reasons, “Think about it: If I were to give up, I would be at a standstill. But if I were to keep going, I would be closer to my goal than I was yesterday, so if you want something, put in your all to achieve it.”

Hema is also thankful that Club Rainbow gave her the opportunity to befriend other children with congenital conditions and showcase her dancing prowess at various events. She said: “There were times when I felt that my passion for such a traditional art form would not extend beyond my Indian community. Club Rainbow made me realize that Bharatanatyam is an art form that can be appreciated by everyone. I would be honoured to return to Club Rainbow one day to teach dance or give tuition.”



SMALL IN SIZE, BIG IN HEART

Javier Tan 10 YEARS OLD

DIAGNOSIS:
Fanconi Anaemia

At first glance, 9-year-old Javier Tan may not be immediately apparent to an onlooker that he is the elder of Ms. Vivian Ho's two sons.

Javier is smaller-built than his brother, Javen, who is four years his junior. He is also exceptionally tanned, which sometimes draw questions from others. If people ask, Vivian, may joke that the boy loves heading outdoors.

Unknown to most people, Javier is diagnosed with Fanconi Anaemia (FA), the commonest type of inherited bone marrow failure syndrome.

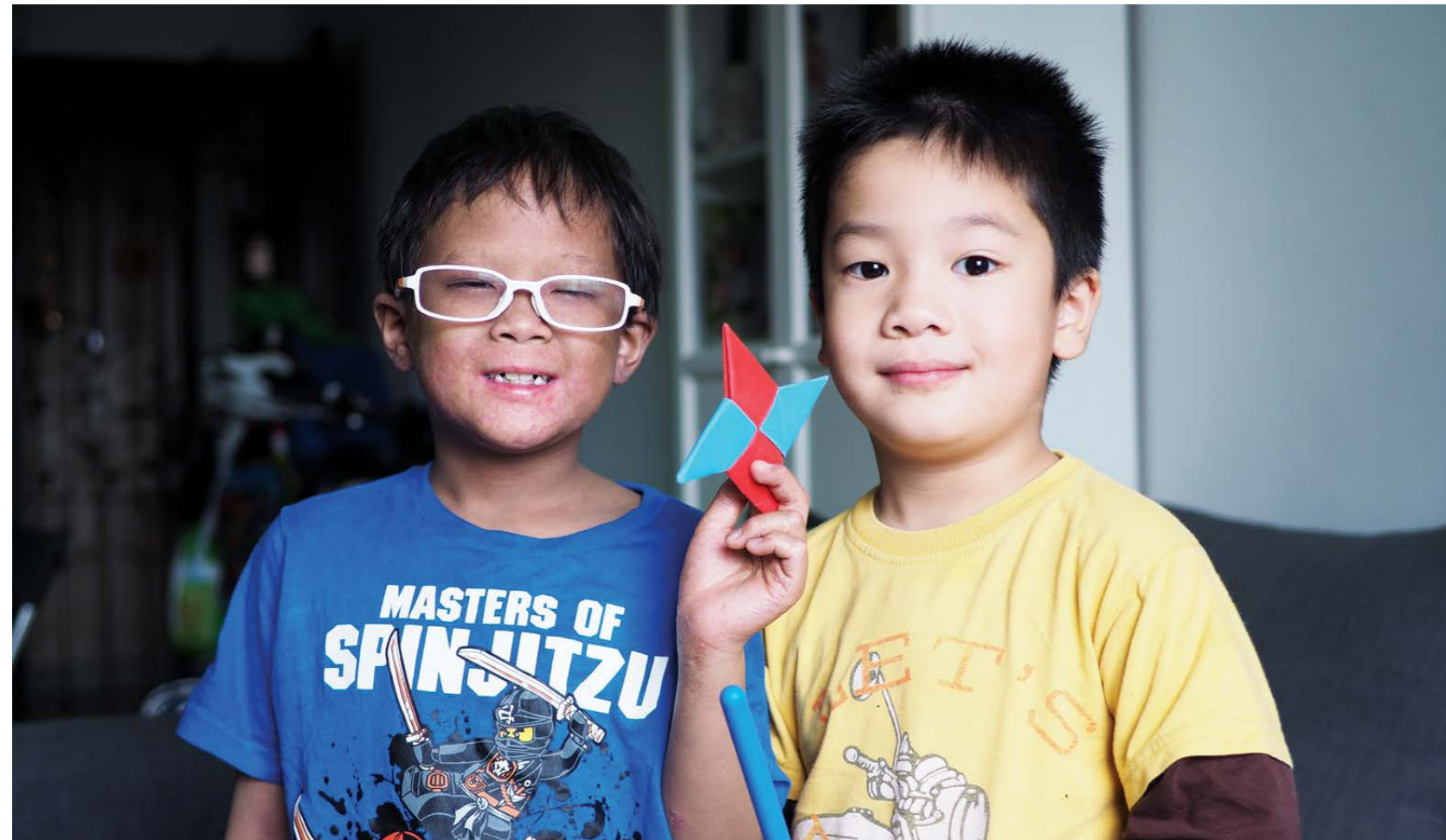
Research has shown that at least 60 per cent of people affected by Fanconi Anaemia are born with at least one physical anomaly. For Javier, it is his short stature, an extra right thumb and skin discoloration which gives him a suntanned look.

When Javier was 3 years old, blood tests showed that he had low levels of all three types of blood cells: Red blood cells, which carry oxygen to the body's tissues; white blood cells, which fight infections; and platelets, which are necessary for normal blood clotting.

Unknown to most people, Javier is diagnosed with Fanconi Anaemia (FA), the commonest type of inherited bone marrow failure syndrome.

Research has shown that at least 60 per cent of people affected by Fanconi Anaemia are born with at least one physical anomaly. For Javier, it is his short stature, an extra right thumb and skin discoloration which gives him a suntanned look.





“ I knew that he felt frustrated then, yet I could also see that he is a strong boy. He is cooperative when it comes to receiving treatments and I always tell him that tomorrow will be a better day.

Vivian, Javier's mother

A stem cell transplant - which replaces defective bone marrow with a healthy donor's - was Javier's hope of increasing his life expectancy beyond the projected median of approximately 30 years old.

In preparation for his first stem cell transplant in December 2014, Javier, then 7, underwent chemotherapy and radiation therapy to weaken his immune system. This helps to prevent it from attacking the donated cells after the transplant. His

mother saw that Javier was losing his hair, so had his head shaved bald.

Unfortunately, Javier was struck by a bone infection that same month, which threatened an amputation and caused him excruciating pain. Vivian recalled how the ordeal was over only after 12 continuous weeks of regular wound debridement and medication.

Javier had his second stem cell transplant on January 31, 2015, using his father's donated blood. This time, he developed graft versus host disease affecting his skin.

Vivian said, "He wore special clothes that kept his skin moist to help alleviate his itch. I called him the cream person because we applied steroid cream all over his body too.



Javier is smaller-built than his brother, Javen, who is four years his junior. He is also exceptionally tanned, which sometimes draw questions from others. If people ask, Vivian, may joke that the boy loves heading outdoors.

"I knew that he felt frustrated then, yet I could also see that he is a strong boy. He is cooperative when it comes to receiving treatments and I always tell him that tomorrow will be a better day."

During the 8 months that Javier was warded at KK Women's and Children's Hospital (KKH), he became close to the hospital staff. He entertained the nurses by moving his limbs and dancing for them. He also kept in touch with younger brother, Javen, through video-conferencing and wrote a letter home every week.

Vivian also got Javier to keep a journal in his ward to pen his thoughts and collate the well-wishes that others wrote for him.

Javier returned to school in April 2016. Club Rainbow's social worker, Sylvia, helped to find a private tutor for Javier, then in Primary 3, to catch up with his schoolwork.

In December 2015, the family of four went on a three-day, two-night cruise to Malaysia with Club Rainbow. Vivian and her husband found the health talks useful while the two brothers enjoyed the games.

When asked if she has any messages for parents with chronic illnesses, Vivian has this piece of advice, "Always look ahead for your kids and yourselves".



A MOTHER'S LOVE

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Er Wen Hao
22 YEARS OLD

DIAGNOSIS:
Autism Spectrum Disorder, Epilepsy,
and Global Developmental Delay

My eldest son, Wen Hao, turns 22 in 2017. He lives with Autism Spectrum Disorder, epilepsy, and Global Developmental Delay. We received the initial diagnosis when he was just 2 years old.

I remember feeling incredibly sad and confused when I heard the news. He was our first child, and as new parents, his condition was overwhelming and difficult for us to understand and cope with. Wen Hao exhibited many of the classic symptoms of autism. He made no eye contact, refused to speak, and communicated through inarticulate noises. He cried at his own birthday parties. His tight oral muscles prevented him from spitting or opening his mouth for feeding and brushing. He was trapped in a separate world of locks and keys.

In his developmental years, we tried a litany of therapies – I took him for physical therapy, occupational therapy, applied behavior analysis, BrainGym, and Montessori classes, in a bid to improve his condition.

He was placed on a gluten-free diet for two years. Unfortunately there is no panacea for autism, and so much of our caregiving consists of meeting his daily living needs. With the help of a hired domestic helper, I ensure that he is well fed, that his medication is taken, that he is clean, and that he engages in meaningful home-based learning activities.

Wen Hao lives with Autism Spectrum Disorder, epilepsy, and Global Developmental Delay. He received the initial diagnosis when he was just two years old.



“ You must simply give your best for the sake of your special needs child, who cannot do much for you, but who needs your love. Learn to enjoy his presence by your side.

Wenhao's mother

Club Rainbow (Singapore) has been instrumental in his growth as a person. We first benefited from Club Rainbow's support when he was hospitalized for a low platelet count during the SARS outbreak. Then, the Club Rainbow staff at National University Hospital (NUH) were quick to offer their support. Since then, Wen Hao has received numerous awards and subsidies from Club Rainbow, such as the TDF Awards for Special Needs, subsidies for his swimming classes, and, most recently, the Caregiver Award.

But more importantly, Club Rainbow has created an invaluable network of support for Wen Hao, me, and my family. Thanks to Club Rainbow's efforts, Wen Hao has attended countless workshops on deejaying, art, and ukulele playing. He has also had the opportunity to go on cruises with my family to Port Dickson, and stay at hotels in Kuala Lumpur, Batam, and Malacca. These are opportunities that, as a special needs child, he would otherwise never have had access to. Through these activities, we have met passionate volunteers and board members who give their all to care for Wen Hao. Club Rainbow empowers children like him to live a meaningful life, enriched with dignity and purpose. We owe much to the words of encouragement and kindness of everyone in the Club Rainbow family.

Today, Wen Hao remains shy, and likes organisation and structure. He no longer throws temper tantrums like he used to. He is fascinated by radios and CDs, and enjoys listening to music. He is a natural in the water, and has benefitted greatly from regular swimming lessons, which have served to stabilise his epileptic fits, and which have been enabled by the Talent Development Fund awards received from Club Rainbow over the years.

Although he has made progress, it is often difficult to keep my spirits up. I am motivated by the desire to give the best care that I can. My dream is that he will be able to take care of himself. My fear is that he cannot, and I am anxious about who will care for him when I am no longer around to provide that attention. Most of all, I worry about how to nurture him when his nature is fundamentally atypical; his special needs require a different plan with goals and actions. I hope to care for him for as long as I am able-bodied, and that his four siblings will do the same when I am unable to.

I would like all parents of special needs children to know that this journey will pass. You must simply give your best for the sake of your special needs child, who cannot do much for you, but who needs your love. Learn to enjoy his presence by your side. This is life.

On her 25th anniversary, it is my wish that the Club Rainbow family will continue to grow bigger and stronger, to reach out to ever more beneficiaries and their families around Singapore, so that they too can feel the warmth and care of an inclusive and loving community.

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HOPE AT HEART

Lim Jun Rong 5 YEARS OLD

DIAGNOSIS:
Atrial Septal Defect (ASD) & Ventricular Septal Defect (VSD); Neurofibromatosis Type 1 (NF1)

Lim Jun Rong was born with an Atrial Septal Defect (ASD) & Ventricular Septal Defect (VSD), or a congenital condition more commonly referred to as “a hole in the heart”. At only 11 months, Jun Rong had to undergo an open-heart operation to surgically close both the holes which would otherwise impede his physical growth.

“**W**hen the heart isn’t beating well, it gets tired. So when he’s drinking milk, you can see that he’s perspiring - it gets very tiring, so he gives up drinking. He wasn’t getting the nutrition he needed,” recalls Jun Rong’s father, Mr. Lim. “His weight loss was an indication that there were no

signs of the holes closing, so the doctors decided it was time for the surgery,” adds his mother, Mrs. Lim. “He had at least seven tubes running in and out of his body... It was quite painful to see.”

The experience has been a test of courage and inner strength for both parents and their youngest son. “He’s been through a lot,” sighs Mrs. Lim, scrolling through old photos of his surgery which she had captured on her phone. “I took these because I thought it’s very meaningful - I want to let Jun Rong know that he went through such a major challenge, at a very young age.”

In spite of the challenges he has faced, Jun Rong is a happy boy. The 5-year-old toddler is chatty and cheerful, blissfully immersed in his collection of toy cars and helicopters. “He’s evolving - he used to be pretty shy. He’s a lot more sociable now. When he sees a stranger, he’ll say ‘Hello!’,” laughs Mr. Lim. They accredit this improvement to the speech development classes which Jun Rong has been attending.





However, the young boy has yet another larger hurdle to face in time to come. While monitoring his heart condition, the doctors have also discovered that Jun Rong has Neurofibromatosis Type 1 (NF1), a rare genetic disorder. It is characterised by the development of benign tumours and “cafe-au-lait spots” (brown discoloration) on the skin.

“It’s hard to say what I felt. Initially I asked myself why he was like this - his two older brothers are totally normal... Nobody can really explain, it doesn’t run in the family,” Mrs. Lim shares. Recalling a recent newspaper article where a man with NF1 was publicly shamed and discriminated against, it is hard for her to hold back her tears. As

In spite of the challenges he has faced, Jun Rong is a happy boy. The 4-year old toddler is chatty and cheerful, blissfully immersed in his collection of toy cars and helicopters.



treatment for NF1 can only be properly administered once Jun Rong’s condition matures, the situation plays out like a tense psychological waiting game, burdening the mind.

For now, the family has developed a strong sense of resilience. Between juggling the demands of challenging career and looking after her two other sons while monitoring Jun Rong’s condition, Mrs. Lim has discovered a new inner strength, which is characteristic of the modern career woman. “This has actually put a lot of burden on us; but it’s okay, we can survive with that,” affirms Mrs. Lim. “We are prepared to do whatever we can for him.”

Events organized by Club Rainbow, such as the annual Royal Caribbean Cruise and the movie screening of the animated film “The Minions”, have presented the family some welcome respite and also opportunities to bond. “I appreciate Club Rainbow for arranging activities like these

“ I think it’s to face it with courage, and to appreciate the good things like the child that we have and the good things he brings to us - he’s very smiley. I think he does bring a lot of joy for us.

Junhao’s parents

- it’s not something we would otherwise find time to do ourselves,” admits Mrs. Lim. “It’s a controlled environment,” adds Mr. Lim. “If he were to throw a tantrum, the understanding would be there.” Exposure to other families with children of special needs has also taught their older sons the importance of compassion and to have a greater appreciation of life.

For both parents, their hopes for the future are simple: for Jun Rong to grow up to be resilient, and for the ties of brotherhood amongst their kids to remain strong. “I hope that he grows up a happy child, that’s all I ask for,” smiles Mrs. Lim.

STRIKING A BALANCE

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Nicholas Heng
13 YEARS OLD

DIAGNOSIS:
Cerebral Palsy

While Madam Yee was pregnant with Nicholas, she encountered problems with her pregnancy and in the seventh month, Nicholas was born prematurely. Although the baby did not require neo-natal care, things did not go well. Madam Yee recalled, "We realised that Nicholas wasn't developing normally after five months but we were told by the doctor that there is nothing wrong with him." When he turned 1, a private specialist was consulted and Nicholas was diagnosed with Cerebral Palsy. The young mother was devastated, "I felt hopeless."



When Nicholas was 5 years old, he needed surgery to loosen the stress on his leg muscles in six areas. This was a difficult and very trying time for Madam Yee and her husband. "Post-surgery for one month, I hardly slept as he needed to be turned regularly to prevent bed sores." As Nicholas became older, the home

physiotherapy sessions have been replaced with exercises on a stationary bicycle.

Nicholas attends a mainstream school as his parents want him to adapt to a real world of able bodied people. Going to school requires Nicholas to walk part of the way using two walking sticks and then in a wheelchair pushed by his father. In addition to having to cope with his physical condition, the young Nicholas was also bullied and taunted by his school mates. The situation was worst when Nicholas was in Primary 3 and the entire class turned against him. Madam Yee was in despair and struggled to cope, "On one hand, I wanted to discipline Nicholas at home but I didn't realise that he was stressed out at school and I was adding to his stress. Nicholas became withdrawn, tore his exercise books in frustration and even scratched me in retaliation." The school introduced Madam Yee to a counsellor and arranged for a special needs teacher from MOE to advise her. "After that, I learnt to



“ Thank you Club Rainbow for helping me all these years. Thank you for the friends that I have made and helping to make me happy. I would one day like to come back to Club Rainbow to help other kids.

strike a balance in caring for a special needs child while teaching him to be independent.” At this time, she was introduced to Club Rainbow (Singapore) who provided emotional support.

Nicholas attended art therapy workshops organised by Club Rainbow which helped to calm him down. In the last three years, he has enjoyed the various workshops which included, robotics, Manga drawing and even a stint as a radio deejay. He has made many friends from the workshops and Camp Rainbow. He has also developed many interests and hobbies. "I like reading and listening to music. I can now repair and fix iPads and computers." Nicholas enjoyed the Camp Rainbow excursions as he got to go to new and interesting places such as KidZania and Gardens by the Bay. Such outings also taught him to be independent. Despite his physical limitation, he took part in the 48th Annual Sports Meet relay game organised by Cerebral Palsy Alliance Singapore (CPAS) for children with disabilities and came in first. He also participated in a swimming competition in August 2016. To help Nicholas prepare for the important PSLE, he also attends tuition classes arranged by Club Rainbow.



Madam Yee, who is the primary care giver for Nicholas, also benefited from the care givers' workshops organised by Club Rainbow. "Club Rainbow has given me a lot of strength and support. When I meet other families with disabled kids, I am inspired by them." She recalled the most memorable time was the cruise to Port Klang, "All the logistics were very well taken care of for all the children in wheelchairs. I could relax."

"Now that Nicholas has improved and learnt to overcome his challenges, I hope as he grows up, he will build on this strength to continue to overcome future challenges," Madam Yee pondered. "I appreciate what Club Rainbow has done – so much resources put in to



Nicholas attends a mainstream school as his parents want him to adapt to a real world of able bodied people. Going to school requires Nicholas to walk part of the way using two walking sticks and then in a wheelchair pushed by his father.

organise the events and workshops. Club Rainbow has helped me during my darkest period. They are like angels," revealed a very grateful Madam Yee. Her advice to other parents with disabled children, "Be grateful for what you have."

The well-adjusted, bubbly and effusive boy hopes to be a reporter when he grows up. Nicholas has this to share with other children with similar challenges, "Ignore what others say. Don't let them stress you. Work hard for the future. If you fail, don't give up." Lastly he also added, "Thank you Club Rainbow for helping me all these years. Thank you for the friends that I have made and helping to make me happy. I would like to come back to Club Rainbow to help other kids one day."

A LITTLE HERO STANDS TALL

Abdul Qayyum bin Rahmat
9 YEARS OLD

DIAGNOSIS:
Lamellar Ichthyosis (Collodian Baby Syndrome), Anhidrosis, short-sightedness, stiffening & restricted mobility of joints

The ever-spirited Qayyum and his mother, Sharifah share a close, loving bond that resonates with the rest of the family.

Qayyum is as you would expect any other 9-year-old to be: A jovial, playful boy with a gleeful devotion to superhero action figures and pizza. However unlike most other children his age, Qayyum was born with a genetic skin disorder called lamellar ichthyosis. Characterised by severe dryness and flaking of the skin, the condition also plays host to secondary effects such as the inability to perspire and short-sightedness.

"I was so shocked," recalls Sharifah, of his birth. "I didn't expect it when the doctor explained to us; I was very sad."

"But the thing is, my husband Rahmat and I knew it was a challenge - for us, we think that if God gives us a challenge, it's because we can handle it."

With great faith and enduring patience, Sharifah and Rahmat managed to overcome what seemed like an insurmountable task at the beginning. "When he was a baby, there was a lot of stress on me... He kept crying and we didn't know why, because he couldn't tell us what was wrong," shares Sharifah. Rahmat recalls the period, with tenderness,

Qayyum was born with a genetic skin disorder called lamellar ichthyosis. Characterised by severe dryness and flaking of the skin, the condition also plays host to secondary effects such as the inability to perspire and short-sightedness.



“From the very first day when our son was born, our lives have been a never ending education... A huge part of our lives is really all about readjusting because of the attention that Qayyum requires.” They adopted common-sense solutions like regularly applying moisturizer to his skin for Qayyum to cope with the physical discomforts arising from his condition. Playtime has been limited to indoor activities like painting and drawing, which he has since developed a talent for.

Perhaps the greatest struggle faced by both parents and child is the harsh discrimination they continue to encounter on a regular basis stemming from people’s misconceptions about Qayyum’s skin disorder. With a heavy heart, Sharifah recalls an incident where she faced prejudice at a school Qayyum was once enrolled in. “I was very disappointed, very sad... I was actually down with depression, always crying in the middle of the night.” Qayyum has experienced his share of bullying, with previous incidents of name-calling and ridicule from some of his peers in school. “They call me ‘weird’ and ‘nerd’,” shrugs Qayyum. Ignoring them, he chooses instead to focus on his studies so that he can grow up to be like his idol, Ironman.



“ I hope that something would change for these children, a better understanding amongst people in the future... Some people don’t understand these kind of children, especially parents. They are the ones who put colors in the children. What I mean is that, how you tell your children about somebody else who is different... It means a lot.

Qayyum’s mother



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In the face of their daily challenges, the family has gotten closer. “Our lives have changed remarkably,” smiles Rahmat. “We learnt that we have become more emotionally conscious and our two older children had to be mentally disciplined at early teenage years.”

“We have learnt to be more grateful; more patient,” adds Sharifah, “I believe when these things happen, it actually makes our bond stronger. With all this hardship, my children have grown up not being materialistic - they know what is a priority, and what is not.”

Rahmat is equally thankful for the support that Club Rainbow has extended to them at each step of the way. “Although we didn’t know much about Club Rainbow (Singapore) at first, we were really excited with the prospect of meeting people whom we believed are big-hearted to children. In addition to self-development classes, outings held by Club Rainbow have allowed Qayyum to have fun in a loving, unjudging environment. “During those times I saw the faces of every child beaming with joy. I could swear every kid had a fantastic time. And who wouldn’t?” recalls Rahmat. “At Club Rainbow he learns that it’s the human spirit that gives and that matters most. There will be a time when he needs to remember what made him feel special, not who. And truly it’s Club Rainbow (Singapore) and her people that made it happen.”

Sharifah shares in her husband’s hopes for the future, citing a greater need for public awareness of children with special needs. For now, she is content with the boy Qayyum is growing up to be, day by day. “He is very brave... We hope that as he grows up, he will give back to Club Rainbow one day.”

UNITY IS STRENGTH

Celebrating 25 years of Club Rainbow

Embrace, Enable and Empower

Toh Wee Yang
18 YEARS OLD

DIAGNOSIS:
Muscular Dystrophy

At the age of 7, Wee Yang was diagnosed with muscular dystrophy, a disease that causes progressive weakness and loss of muscle mass. While symptoms vary, some people with muscular dystrophy lose their ability to walk, and may have difficulty breathing or swallowing. Wee Yang was diagnosed with the most severe form of the illness, where deterioration was most rapid.

When Wee Yang was in kindergarten, his parents noticed that he seemed to fall down quite often, but they did not think anything of it as it is part of the growing up process in young children. However, when he entered primary school, the school nurse noticed that he had trouble squatting as well as climbing the stairs and so advised his parents to send him to the hospital for a full-body check-up. What the Toh family did not expect, was the doctor's eventual

diagnosis. At the age of 7, Wee Yang was diagnosed with muscular dystrophy, a disease that causes progressive weakness and loss of muscle mass. While symptoms vary, some people with muscular dystrophy lose their ability to walk, and may have difficulty breathing or swallowing. Wee Yang was diagnosed with the most severe form of the illness, where deterioration was most rapid. Wee Yang had difficulty standing and walking by the time he turned 8. By the time he was 9 years old, he was wheelchair-bound.

Wee Yang's mother, Madam Ong, describes the family's reaction. "We did not know what muscular dystrophy was. We had difficulty accepting the diagnosis; we had never heard of this illness. We did not know how to deal with it."

Getting emotional, she shares, "When I think about it, the tears just flow. Even after all these years, it is difficult to talk about it."



Over the next few years, Wee Yang's condition worsened and he encountered other medical challenges associated with muscular dystrophy. The doctor advised Wee Yang's family to let him undergo corrective spinal surgery for the curvature of his spine, which was compressing his lungs and causing repeated lung infections.

Madam Ong describes the days leading up to the operation, "Wee Yang cried the night before the operation because he was scared, but when I asked him about it, he told me his eyes were wet because he had washed them. He did not want me to worry."

“All the best to Club Rainbow on your 25th anniversary! Continue to help more people like me.”

Wee Yang is a very thoughtful and considerate boy.”

These qualities, along with his positivity, are evident in conversation with Wee Yang. When asked what gives him inspiration or motivation in life despite the challenges faced, Wee Yang responds, "I live each day as it comes. I do not really have a plan. I just try to be happy. I do not think so much. I laugh more."

This positive mind set has been necessary to face many of the day-to-day obstacles that Wee Yang and his family must face. Despite the surgery, scoliosis set in about a year after the operation and Wee Yang lost the ability to take care of his own needs.

Madam Ong reveals, "Wee Yang is now completely reliant on me. I have to feed him at every meal before I can eat. As Wee Yang cannot turn by himself in his sleep, I have to wake up and turn him multiple times every night. He cannot stay in a fixed position for long periods as his limbs will go numb. I have not slept through the night for a long, long time."

Wee Yang requires assistance to perform daily activities, and he has suffered from breathing difficulties due to repeated lung infections. To add to this, his parents are also facing their own medical conditions. Madam Ong suffers from nerve and joint disorders from years of moving and carrying Wee Yang.

Club Rainbow (Singapore) has helped to lift some of the burden off the family in caring for Wee Yang. Wee Yang and his family first learned about Club Rainbow through an NUS social worker who happened to be an ex-beneficiary of Club Rainbow.

In a voice laced with gratitude, Madam Ong says “Club Rainbow has helped us a lot. They have provided both financial and transportation support to us. Wee Yang gets home-based physiotherapy once every two weeks and we get food rations, including milk and diapers as well. We have also gone for a number of programmes to watch the fireworks and even to have dinner at Orchard Hotel. Wee Yang has also won several educational bursary awards given out by Club Rainbow”

Wee Yang adds, “Club Rainbow organises fun activities. I really enjoy attending the programmes. The most memorable event I attended was a trip to the Trick Eye Museum. We took many interesting photos. Another memorable event was when we attended the family retreat on a cruise. It was the first time our whole family was able to travel overseas together.”

Additionally, Club Rainbow has connected Wee Yang and his parents with a network of other families. Madam Ong explains, “We support and ask after one another.

Sometimes the other families will call to check on us.”

When asked about his plans for the future, Wee Yang who has just completed his O-levels divulges, “I plan to study Multimedia and Info-communication technology in Nanyang Polytechnic (NYP). I like computer-related stuff. There will be challenges, given NYP is located further away from my home and lessons will be conducted lecture style, but I am looking forward to starting school.”

Being able to achieve these goals while facing the enormous physical challenges brought on by muscular dystrophy, is testament to the strength and resilience of Wee Yang as well as the support he has gotten from his family. When asked if there is anything he would like to say to his parents for all they have done for him, Wee Yang turns coy and reticent, like any normal teenager his age, saying only, “Thank you for everything.”

Wee Yang continues “All the best to Club Rainbow on your 25th anniversary! Continue to help more people like me.”

Wee Yang’s mother echoes this sentiment, saying, “We hope that Club Rainbow can continue to help more children with chronic illnesses.”



When asked about his plans for the future, Wee Yang who has just completed his O-levels divulges, “I plan to study Multimedia and Info-communication technology in Nanyang Polytechnic (NYP). I like computer-related stuff. There will be challenges, given NYP is located further away from my home and lessons will be conducted lecture style, but I am looking forward to starting school.”

RISING ABOVE DIFFICULTIES IN LIFE

Siti Zulaikha Binte Mustafa 8 YEARS OLD

DIAGNOSIS:
DiGeorge Syndrome / Failure to Thrive / Global Developmental Delay

Muhammad Hakimi Bin Suhaimi 4 YEARS OLD

DIAGNOSIS:
Down syndrome / Hearing Loss Bilateral / Developmental Delay

Siti has been diagnosed with DiGeorge Syndrome, a genetic condition caused by a defect in chromosome 22, which is characterised by poor development of various body systems including the heart, immune system and blood. She also suffers from behavioural and emotional problems caused by Global Development Delay. Her brother, Hakimi is also a special needs child. He has Down Syndrome, bilateral hearing loss and developmental delay.

On the surface, 8-year-old Siti Zulaikha looks no different from other children. She watches cartoons, dances along to tunes from online videos and loves to eat Maggi mee. But the scars on her tiny body are testament to the numerous operations she has had since birth, likely more than what most people would have undergone in their lifetime. Siti has been diagnosed with DiGeorge Syndrome, a genetic condition caused by a defect in chromosome 22, which is characterised by poor development of various body systems including the heart, immune system and blood. She also suffers from behavioural and emotional problems caused by Global Development Delay.

In addition to DiGeorge syndrome, Zulaikha had Trunkus Arteriosus, a complex cardiac abnormality for which she underwent major heart surgery at five months old. She also suffered from gastroesophageal reflux disease (also known as GERD) and had to have a tube inserted into her stomach for feeding soon after birth.

Zulaikha recently had the tube from her stomach removed, and can eat small amounts of food very slowly, but the wound has yet to close, and doctors are planning to put her through another operation to close it soon.

Zulaikha also has a 3-year-old half-brother, Muhammad Hakimi Bin Suhaimi. The siblings stay together in their maternal grandparent’s home.





Hakimi is also a special needs child. He has Down Syndrome, bilateral hearing loss and developmental delay. Bubbly and active, Hakimi has the never-ending energy of a typical 3-year-old, always on the lookout for something to climb over and a toy to throw.

The family's sole breadwinner is the siblings' second aunt. The children's 52-year-old grandmother, Madam Halijah, chips in by baking cookies to sell on special occasions such as Hari Raya. Medical problems are not new to the family, as the children's uncle is currently suffering from leukaemia, and their grandfather is very ill. The children are taken care of primarily by their maternal grandmother, Madam Halijah, as their mother is unable to care for them.

Despite the fact that raising two special needs children almost single-handedly is difficult, their grandmother never regrets having them around and life carries on. Her greatest fear is for herself to fall ill, because she knows she is the pillar of support for the whole family. She has ignored the pain in her leg and has refused to see a doctor for fear that the diagnosis would be something serious. When talking about the possibility of herself falling sick, the children's grandmother starts to choke up, asking simply, "What will happen to the children if

“ I'm grateful for all the assistance and services given by Club Rainbow to my grandchildren and my family. Club Rainbow has helped me a lot throughout these years. I wish that Club Rainbow will always be successful, to keep on growing and to expand for the better. I hope that they will continue the services to those in need.”

Mdm Halijah, Zulaikha & Hakimi's grandmother



anything happens to me?" It is clear that she is the lynchpin in the family; everyone looks to her for direction.

Mdm Halijah's daughter, 20 year old Erma, is one of the most important people in the children's lives. She is very close to them, coming home immediately after school to play with, feed, and tuck them in at night, eschewing the chance to go out and have fun with her friends most of the time. Despite her youth, Erma is self-sufficient, using money she earns in the holidays to fund her studies and extra-curricular activities. The entrepreneurial young lady, who is studying at ITE, has even started a fundraising project in conjunction with the Singapore Discovery Centre, selling various craft items to raise funds for Club Rainbow (Singapore).



Despite the fact that raising two special needs children almost single-handedly is difficult, their grandmother never regrets having them around and life carries on. Her greatest fear is for herself to fall ill, because she knows she is the pillar of support for the whole family.

Club Rainbow has been providing financial assistance to the family, in addition to dispensing food vouchers, milk powder and other necessities for the children. Social worker, Janeth, who visits the family once a month, provides invaluable emotional support to the family. She listens to their problems and offers advice where necessary, forming an important aspect of the support network that families require in raising special-needs children.

Over time, it has become clear to the family that the children are not much different from other "normal" kids. They talk, laugh, and love in very much the same ways, teaching their family to be more patient, more resilient and stronger together than they were before. Even though the adults have their hands full taking care of two special needs children, they consider it fulfilling. In fact, they cannot imagine life before the children were born.

VOICES FROM OUR HEART

“ I derive much job fulfilment and satisfaction from working with my clients and who excel in their studies, especially in ITE, despite their chronic illnesses. One of my clients shared, “I have to prove to my classmates that I have the same learning capacity as them despite of my chronic illness.” It is encouraging to see them take pride in their studies and being motivated to develop their potential to the fullest.

Ms Sylvia Mak (Principal Social Worker)

“ The greatest reward that spurs me to continue working to help our beneficiaries and their families is this simple phrase from one of our beneficiaries: “Thank You for being there with us.”

Ms Sally Ong (Executive, Client Service)

“ Having been in Club Rainbow (Singapore) for the past four years, I have done many programmes/ events and seen the kids grow up. Some of them became more sociable and discovered hidden talents such as drawing & painting after attending our programmes and workshops. It is also very heart-warming when parents come to me and update me about their kids’ progress and how they are really grateful that Club Rainbow provides these programmes. It’s these little things that motivate me every day.

Ms Shaikha Nadiyah (Executive, Programme Development)

“ I have been truly blessed to be part of Club Rainbow (Singapore) in this enriching journey to bring joy and support to our beneficiaries and their families. One magical moment was when I was involved in the Dreamseeds Concert in 2015. I saw our children’s excitement from getting ready to go on stage to putting on remarkable performances in front of a huge audience. It felt amazing to witness their efforts on this magical wonderland platform where they accomplished personal feats. Seeing the delighted faces of our children and their families was truly priceless.

Although my job requires no direct involvement with beneficiaries, I try to strike little engagement points with them, their siblings and their families whenever I see them at our centre or during events. Though contact opportunities are minimal, every touch point is heart-warming. Their glowing smiles, enthusiasm in learning and the opportunity to be part of their journey are wonderful reminders of why I work in Club Rainbow!

Ms Christine Tan (Senior Executive, Human Resource)

“ I am thankful for the opportunity to journey together with our beneficiaries and their families. To know that I am able to help them in any small way is one of the greatest rewards for me. Walking alongside with them has taught me the true value of things and I am extremely grateful for all that I have. The rewarding experience of serving our beneficiaries and their families have indeed shaped me to be a better person on both a personal and professional level.

Ms Sandi Tan (Senior Social Worker)

VOICES FROM OUR HEART

“ Having volunteered at Club Rainbow (Singapore) since 1996, I have the privilege of seeing it grow from strength to strength. What started out as a youthful enthusiasm to contribute via Camp Rainbow has morphed into two decades of involvement in what can only be described as an immensely fulfilling journey with Club Rainbow (Singapore). Many have asked what got me started at Club Rainbow (Singapore) and what kept me going for so long. Between a pretty hectic full-time job and an ever-increasing family commitment, there are frankly many good reasons to quit. There are, however, three simple reasons why I kept going on.

First and foremost, it is because I can. Those of us who have been fortunate in life have a moral obligation to aid those in need. Having the ability to help is a great blessing, use it freely.

Secondly, it is the people involved at Club Rainbow (Singapore). The energy of like-minded volunteers, working with committed full-time staff, to provide what we coined “Compassionate Relevant Services” to our beneficiaries, is both infectious and addictive. While the first reason is what got me started, the second reason is what kept me going.

The final reason is that volunteering gives me a perspective on life like no other. This is best explained via a real experience at Club Rainbow (Singapore) that is poignantly etched in my mind. Many years ago, I was having a meeting at work to discuss the budget for our company’s annual party when I was interrupted by a call from a staff at Club Rainbow (Singapore). The parents of one of our beneficiaries, a seriously ill teenager who had been on life support, had decided to take her off it on her birthday, which was in a few days’ time. Her Club Rainbow (Singapore) befriender got to know about it and wanted to throw a birthday party for her so that her friends could get the chance to say a final farewell. The staff wanted to know if she could have the approval for Club Rainbow (Singapore) to fund the \$200 needed for the party. Having just been in a meeting where we were discussing spending thousands of dollars on a fancy year-end party, this request was sobering and put things in perspective. We often get so engrossed in our own circumstances that we lose sight of what is truly important or dear. I am a firm believer that volunteering, besides helping others, also keeps us humble, real and grounded.

All of us have the ability to help in some way, shape or form. We just need to take that first step. To quote Arthur Ashe, “Start where you are. Use what you have. Do what you can.”

Mr Eric Teo, Vice-President

“ Ride for Rainbows has been our public fundraising cycling event for the past six years. It has seen tremendous growth in size and funds raised each year and I had the privilege of working in the main organizing committee for four consecutive years. Every year, our staff would be involved on the event day by contributing in their roles and working through the wee hours to make the event a success. Together with our Management Council members, donors, sponsors and volunteers, it is the ONE main event where we see everyone coming together in enthusiasm and team spirit for our beneficiaries and families.

The beneficiaries and families that Club Rainbow (Singapore) serves are most often forgotten and unseen by our society. It is my wish that Club Rainbow, in the next 25 years will continue to make a big difference in the lives of these chronically ill children and their families. In doing so, we would make Singapore a more inclusive and compassionate society for this special group of people.

Mr Ng Thin Hoong (Senior Executive, Systems & Process)

“ There wasn’t one specific reason why I chose to join Club Rainbow (Singapore), but I guess it can be summed up with one of my favourite quotes by Franklin Roosevelt, “We cannot always build the future for our youth, but we can build our youth for the future.”

This is especially true if you look at how the world is changing ever so rapidly. Building our youth is the only way forward - and every youth deserves that chance.

Mr Chow Shang Wei, Fundraising and Marketing Director

WHY
WE
VOLUNTEER

“ It was an extremely humbling experience going through these stories. From the family’s realisation of their child’s condition at birth, to how they grappled with the situation, the courage they displayed and how each family comes together to overcome the challenges.

Thank you Club Rainbow for the opportunity to work on the book and thank you for making a difference in the lives of children with chronic illnesses and their families.

Roy Chua (Volunteer writer)

“ In 1994, I came to host a Club Rainbow event with trepidation and anxiety because I wasn’t sure how I was going to host effectively. But on that fateful day, I was taught by the beneficiaries; their sheer positive attitude, what life is about and how much more I need to change my attitude about Life. And that is why till today, I continue to host their events whenever possible.

Gurmit Singh, a long-time supporter of Club Rainbow (Singapore)

“ Once, I assisted a beneficiary with answering some questions at the end of a photography workshop. One question asked was, “What photography technique did you use?” While techniques like ‘framing’ and ‘flash’ came to my mind, the beneficiary gestured to me to convey that he thought otherwise. With much effort, he finally wrote down the word ‘love’. Indeed, love is enough.

Karen Yong (Volunteer photographer)

“ I am thankful and appreciative of the opportunity to interact with the Club Rainbow family. Everyone was welcoming and friendly, making it a familial experience. I had a pleasant takeaway each time and was also inspired by many different individuals. I look forward to participating in the next Club Rainbow event.

Khaw Yeejek

“ When I wrote the beneficiaries’ stories it opened my eyes and made me appreciate the things we usually take for granted. It also brought new meaning to unconditional love – caring for a grown-up child who is totally reliant on you and who will never be able to hug you or say, ‘I love you’.

Lui Suit Cheng

WHY WE VOLUNTEER

“ I’m honoured to have been a part of the creation of Club Rainbow’s 25th anniversary coffee table book. This is my first time working with Club Rainbow and I was overwhelmed by the kindness and compassion of the social workers and the warmth from the families. I could truly see the genuine relationship everyone shared. Happy 25th birthday Club Rainbow!

Yue Si Wei

“ When you grow up never needing to struggle with health or finances, yet notice that not every child grows up as comfortably, you can’t help but realise how lucky you are... And it makes you want to give back. Every child deserves as much as others do and I hope we can help some of our children struggle just a little less.

Lek Anqi

“ The first child I took a photo of happened to be a boy with Down syndrome. From my observations and discussions, I now better understand the emotional stress, financial strain, and fear of judgment the families go through. My goal is to teach people to see these children as happy kids and not their special needs.

I always go beyond the norm. I do my best to build relationships with each of the families – and even allow the child to try taking photos using my camera. I met these kids and I can imagine their struggles. It really puts things into perspective.

Philip Au

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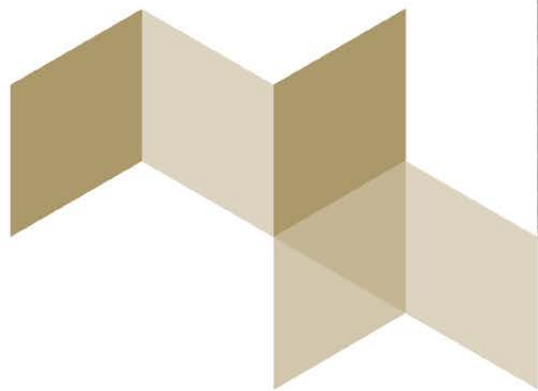
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- *Our beneficiaries and their families*
- *Our Advisory Board members*
- *Our Management Council members*
- *Our Staff*
- *Our Community Partners*
- *Our Volunteers*

Special thanks also go out to the following people for taking considerable time and effort to make the publication of this 25th anniversary commemorative book a success. We wish to extend our heartfelt gratitude to our interviewers, photographers, writers and editors who have put in hours and worked together for these wonderful stories of our beneficiaries that you have read.

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