



RAINBOW CONNECTION



CLUB RAINBOW (SINGAPORE) MONTHLY NEWSLETTER • SEPTEMBER 2018 • ISSUE 8



Feature Story.

Giving back to Community

"Children are our future, our hope..." says Edmund. Find out who he is and perhaps you share the same passion as him?



Celebrating Heroes

As the entertainment circle pays tribute to fictitious superheroes such as Superman, Captain America, Wonderwoman, etc. through the various movie marathons over the weekends, our beneficiaries, too have heroes(silent) in their lives whom we recognise and like to commend their efforts through the Exemplary Caregiver Award and Exemplary Sibling Award.



- Bridge Programmes
- CSR activities
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Giving Back To Community

Left: Mr Edmund Lee
Right: Mr Darwin Ho

Mr Edmund Lee, a familiar name to many parents over the years who will stand to attest his patience, gentleness and confidence assuring presence during the cycling lessons when they visit his humble bike shop in Queen's Road with hopeful hearts of having brave little riders at the end of the training sessions.

Edmund was chanced upon by our team during one of our door-to-door promotion exercise for Ride for Rainbows (RFR) annual event. It was the first time Edmund heard about CRS and yet both he and his wife opened their hearts to hear us out as we explained more about our organisation and the beneficiaries. Almost immediately, he felt connected and the call to support our little ones through RFR.

When asked of his strong beliefs about CRS, he replied "Children are our future, our hope. I believe we should try to support families who have children with special needs because apart from the medical conditions, families are also faced with many challenges brought about through such a situation. I am very glad that CRS is a platform offering various kind of support to these families and I definitely give my utmost support."

A father of 3 children, aged 23, 25 and 29, Edmund had the privilege to experience childhood blissfulness with love from his parents and 4 siblings, without any illness or disability. Through his growing years, he understood that not everyone has the same privilege

when affected by medical conditions. This made him more conscious of families who are in need and to include the notion of giving back to community as part of his life in the later years.

"Life is like cycling, to keep your balance, you must keep moving."

In the past he was very much focused on supporting his family, spending a lot of time on his work life which left him little or no time for any community service. Now with his children all grown up and independent, he is taking the opportunity to kick off his plans for volunteerism even before retirement, striking a balance between both fronts. While we work hard to provide our children with a better quality of life, Edmund feels that we should consider supporting non-profit organisations like CRS who helps children with chronic illnesses and needy families lead a more enriching life. And he wants to use his own network to help as many as possible. "After all, life is very short." says Edmund.

"The contribution by each individual is small as compared to that of an organisation. However, even if it's a small effort, it should be meaningful" commented Edmund. An avid cyclist himself finding that RFR

resonates with his profession and what he has been looking for in community service. He participated in RFR 2018 for the first time. Using his years of network, he managed to garner slightly over \$14K for the fundraising event, emerging as one of the top fundraisers for the event.

Club Rainbow (Singapore) likes to thank Edmund and many other long-time supporting individuals who have been with CRS for many years.

THANKYOU

A special mention by Edmund to Mr Darwin Ho, a fellow rider for RFR for 5 years now (one of our top fundraiser for RFR 2018) as he expresses his thanks. As a first-time participant, Edmund started to encounter cramps caused by low sodium count in his body halfway through the event from cycling long distance. Being a veteran of the event and prepared for such situations, Mr Ho lends a helping hand by sharing some tips of managing cramps and salt tabs. A simple act such as this is welcoming for first-time participants and definitely encourages them to continue fundraising as a family with CRS.

Giving and sharing is the best and beautiful thing in our life. I wish to try my best to help other people till my life ends.

Exemplary Caregiver Award



Caregiver: Soe Thander Zaw and Soe Sanda Zaw
Beneficiary: Sandrine (not beneficiary's real name)

Mr and Mrs Tan have been blessed with a pair of selfless and caring twin sisters – Thander (caregiver of 10 years) and Sanda (caregiver of 8 years) who have been taking care of their first child Sandrine since she was young. It has been a journey that is filled with trying times, tears, happiness, joy and fulfilment taking care of little Sandrine when she was diagnosed with aspiration pneumonia and Global Development Delay (GDD) at about 4 months old, and West Syndrome at 2 years old.

What made you (Sanda) decide to take care of Sandrine for more than 8 years?

My sister told me she has been taking care of a special needs child called Sandrine. I decided to take care of Sandrine because when I see her, I love her; she is very cute and pretty. When I carry her, I feel that she loves me too.

Thander and Sanda took it upon themselves to share the challenges and responsibility of Sandrine's condition with her parents. Toggling between household chores, attending different types of caregiver courses and taking care of Sandrine's younger sister, they still made it a point to be focused, attentive and meticulous towards Sandrine's needs. From helping her to be comfortable during tube feeding hourly, accompanying her for the hospital stays which happens averagely at least 5 times in a year to engaging with her through her favourite music sessions, they will always have her best interest at heart and ensuring her well-being. Constantly, putting little Sandrine before their own well-being, they would sometimes forgo their rest and off days to look after her.

How is Sandrine like? What do you like most about her?

She cannot drink, she cannot swallow and she cannot sit up. She cannot talk but I treat her like a normal child. I always carry her and I play with her. She always laughs whenever I talk to her. She understands and she will respond. She likes singing songs so I will play them for her as well as sing and dance for her. It makes her very happy because she really loves the songs.

Both Thander and Sanda are trained in various aspects like Physiotherapy, Speech Therapy, Music Therapy, Fits Management and Allergy Management, and are capable of providing medical care to Sandrine round-the-clock. Their dedication and commitment to keeping abreast on the development of her medical condition allow her parents to focus on work and to cope with stress better knowing that their baby daughter is in good hands.

Do you have anything to say to Sandrine and her family?

Every day I think about the promise I made to my darling Sandrine. I want to tell Sandrine, "You must be brave and strong. We will be with you forever, together."



Exemplary Caregiver Award

Caregiver: Hung Chiu Ping

Beneficiary: Angelia (not beneficiary's real name)



"We will go through this together" was what Chiu Ping, mother of two children herself said to Angelia's parents when she found out that Angelia was diagnosed with Cerebral Palsy (CP) at 1 year old. Both Angelia's parents and Chiu Ping had no knowledge of this condition. At that point, Chiu Ping took it upon herself to be supportive as much as possible by researching online to understand more about the condition and changing her daily routine with Angelia - taking her to school and medical appointments, doing stretching exercises and especially encouraging play time with her children to motivate Angelia to move. These efforts are paid off, now at 3 years old; Angelia can sit up and move around the house, playing catching games with Chiu Ping's children in her walker.

What are the challenges that Angelia encounters in her development? How do you help her along the way?

She is already 3 years old but still cannot talk and walk so she is unable to attend a normal school. I teach her what other kids of her age should be learning but she is very slow in absorbing what she is being taught.

As Angelia is still very young, she does not know how her condition might impact her life yet. Weighed down by this concern, Chiu Ping is very particular about giving her the same opportunities to learn, grow and adapt as other kids do. She will buy age-appropriate toys for Angelia to explore and play with. Other than movements and speech ability being impaired due to her condition, Angelia has shown that her mental, cognitive development and understanding are on par with children of her age. She can understand instructions such as 'sit properly', 'stand properly', 'bath time' and 'milk time' among others. Thanks to Chiu Ping's conviction and belief, little Angelia is also able to transit from lying down to flipping around and to sitting up.

Do you have any worries or fears about her future?

I'm worried that she cannot be independent in future when she grows up and that she will not have the capabilities to lead a normal life.

Do you have any words of encouragement or advice for other caregivers?

In our work (as babysitters), not all efforts will be duly rewarded but if we don't do what we can, we will definitely not see any results.



Word of gratitude for Chiu Ping's wholehearted love for little Angelia from her parents

"These 2 years we have learnt a lot regarding CP conditions. Without the help and support of Chiu Ping, it would be a lot tougher and less smooth sailing for us. There are too many examples to list them one by one but one thing for sure, under the care of Chiu Ping, Angelia has grown emotionally, socially and most importantly, she is a happy toddler no matter what condition she is in or what challenges she might face in future. She doesn't need to be afraid, because we all including Chiu Ping will be here for her."



Exemplary Caregiver Award



Caregiver: Siti Fadillah Binte Mohamed Noor (Mother)
Beneficiary: Muhammad Sayfullah Bin Mohamad Sahrin

“Don't look at their disability,
look at their ability”

Every child is precious to their parents. A saying that resonates well with Mdm Siti, a mother of three who agrees readily like any other parents do even though when her son, Sayfullah was diagnosed with Quadriplegic Cerebral Palsy at about 9 months-old. It was something very new to her but she was not going to take a back seat approach.

What are the difficulties that Sayfullah faces? How do you help him to overcome them?

Since he has Quadriplegic CP, it has affected his speech, movement and motor skills. We know that he is unable to walk because his four limbs are affected; the muscles are not strong, unlike us. I realise that Sayfullah is into digital things. That is where I have to do more with him, and find out about digital assistive tools that can help him (to be self-sustainable) in future.

Understanding that parents play a vital role in children's education, Mdm Siti tries her best to reach out to available resources, moving from one centre to another for schooling, therapy, etc. which would support Sayfullah's development of self-sufficiency and social skills. Going the extra mile, she proactively sources and trains Sayfullah on adaptive and assistive devices allowing him to build up his independence.

How has Club Rainbow (CRS) been supporting him and your family?

With CRS, I have enrolled Sayfullah in digital drawings with the subsidies from their Talent Development Fund. My other children were also able to receive tuitions and attend enrichment programmes.

What are your hopes for the future?

My hope for Sayfullah is that he could advance and specialize in the field of digital drawing and eventually will be a career option for him. Also, I hope in the future that people will change their mind about special needs. Don't look at their disability, look at their abilities. The muscles may be dead, but the brain is not.



Exemplary Sibling Award



"He ain't heavy,
He's my brother"

Sibling: Muhammad Saifullah Bin Ghazali - Admirable Award
Beneficiary: Muhammad Syafiq Bin Ghazali

Saifullah, now 20 years old and a beneficiary of Club Rainbow (Singapore) himself, understood about his brother's medical condition when he was just 5 years old. Syafiq suffers from Epilepsy, a neurological disorder. Saifullah gets to witness his brother displaying uncontrolled jerking and his eyeballs would roll back during a brief episode of epileptic seizure.

As his brother's keeper, Saifullah is always mindful of the necessary like remembering medication timings, checking on his cleanliness, daily exercises, practising walking, eating and drinking independently. Through Saifullah's dedication and perseverance, activities which are often taken for granted, Syafiq now knows how to drink from a box of ice lemon tea by sucking the small straw, holding a biscuit, eating by his own effort and also doing a short walk.

As a grandson and son, he spends most of his time with his grandmother and mother. Helping out with household chores, offering to send and fetch his brother to school despite feeling tired from working. On his off days, he would choose to spend time with his family instead of having heading out with friends of his age.

How has Club Rainbow been helping Syafiq and your family?

I want to say thank you to Club Rainbow because they have been helping us a lot. They sent me for tuition classes. They even organised family activities such as cruise trips and camping.

Do you have anything to say to your brother and your family?

I want to say thank you to my mother for taking care of my brother and me since we were born. When my mother passes away, I will take care of him until the day I die.

Saifullah is also nominated for the Admirable Award for his tenacity and resilience.

"Never give up easily!"

Amanda Ng

At the age of 5 years old, Amelia came to know that her sister is different and that she has Mitochondrial Complex 3. Like any regular teenager but one who has blossomed through her experience as a sibling to her younger sister who has special needs. She has been very independent, not just taking care of her own needs but also of her sister. Researching on her sister's condition has led to her wanting to be a paediatric neurologist so that she could help children like Amelia, and make a difference.



Sibling: Amanda Ng
Beneficiary: Amelia Ng

You chose home-schooling so that you can have more time for Amelia. What prompted you to make that choice?

During our last overseas trip, Amelia had a near death experience and that made me want to spend more time with Amelia. I want to be there for her. I have to treasure every moment I spent with her.

What are your hopes for the future?

To obtain a genetic report for Amelia so we can find what causes her condition. I want to prevent the same thing from happening to my kids in the future. I pray that if one day I can bring Amelia to see or touch snow, she can be miraculously as strong as the Snowman and her condition will be improved and she can lead a life as pure as snow and free of pain.

Exemplary Sibling Award

Sibling: Sameera Binte Taufan
Beneficiary: Syifaa Yasyaa Binte Taufan

“Be brave and don’t be afraid to learn new things. Be strong and be grateful. Your child or sibling is a special gift from God.”

Sameera Binte Taufan



Eldest daughter of the family, sibling to twin sisters and youngest little sister Syifaa, Sameera couldn’t understand what happened to Syifaa when she learned about her sister’s illness at 9 years old. Over the last 2 years, her mother gradually shared more on the condition and taught her how to look after her little sister. She is able to do basic medical assistance towards Syifaa, performing nose and mouth suctioning when necessary.

Spending most of her day looking after Syifaa leaves her with only time at night to do her homework and during her free time, although she does go out with her friends she would miss her little sister when not around her.

Despite getting less attention from her parents, the love and care that Sameera gives to her sister is unconditional. If taking care of Syifaa had taught her anything that is to be grateful for what she has, be more understanding towards others and to be strong like her baby sister.

Have you ever encountered difficulties? How do you keep yourself going?

I have not encountered any difficulties. However, I am afraid of performing trachea suction for Syifaa. My mother is going to teach me that. I have never felt frustrated. Syifaa and I keep each other company and we keep each other going.

What are your hopes for the Syifaa?

I hope that she will be stronger, never give up and be an inspiration to others in the future.



Sibling: Shaista Farihah Binte Mohd Sahrin (Sister)
Beneficiary: Muhammad Sayfullah Bin Mohamad Sahrin

13-year-old, peaceful and gentle Shaista shows maturity in her thinking and ambitions despite of the challenges she faces. 10 years ago, a mere toddler then was when she learned about her brother’s medical condition and had never competed with her brother for mother’s affections. Remaining very supportive of her mother and brother in all circumstances, she accompanies and assists her mother when they bring Sayfullah for his medical appointments.

Did you have to make any sacrifices for him?

Of course I have to make sacrifices when you love the person. I made a lot of sacrifices but it doesn’t really bother me as long as I make him happy and everyone is happy then I am happy too.

Has taken care of your brother taught you anything?

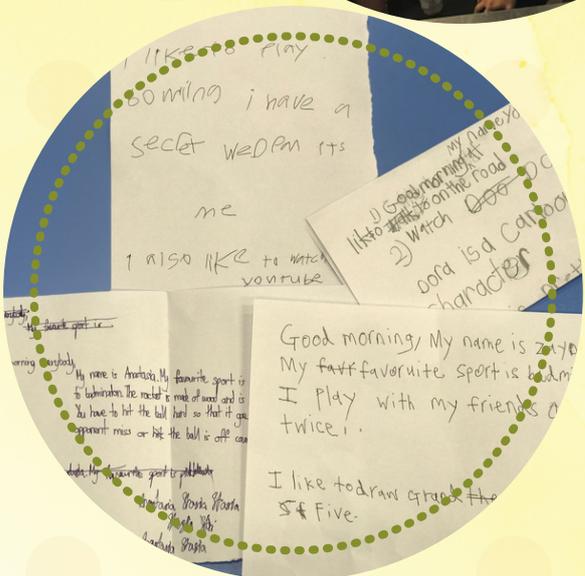
I have learned to be patient, to know what love means and how to take care of other people properly.

Do you have anything to say to your brother and to your family?

I have to say that I love all of them with my whole heart. I will support them no matter what.

Bridge Programmes

LINKWAYS TO
COMMUNITY INTEGRATION AND
INDEPENDENCY BY
DISCOVERING AND NURTURING
TALENTS.



CRS brings together specially curated workshops catering to the various age groups of our beneficiaries and their siblings. These bridge programmes vary from culinary, emcee training, barista training. Some of the selected participants had a chance to showcase their skills for everyone who attended our Celebrating Heroes Event on the 8th of September 2018.

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Gardens By the Bay with
Mirage Aesthetics



A day at Science Centre with
students from Hwa Chung JC



Art Jamming with
Roche Diagnostics Asia Pacific

Workshops



Digital Drawing Workshop - Make The Change

As part of Club Rainbow's Interest-Based Programme (IBP), Make The Change conducted a Digital Drawing Workshop which uses digital arts to promote experiential learning. Participating beneficiaries learnt how to use the iPad Pro and Apple Pencil, providing them easy usage of technology to create art. They will also pick up basic design principles such as visual expressions of ideas, composition and framing, and using digital canvas tools and hardwares to freehand draw designs

Pet Illustrations - Paintinks By Melt

Paintinks by Melt, one of the many companies through CRS' Interest -Based Programme (IBP), conducted a small session teaching our beneficiaries basic shape doodles to create animals and pets.



Selected artworks will be displayed at DSAF 2018 exhibition, and outstanding artworks will be turned into merchandise for sale at the Arts Market.



Children Emotional Resilience Group

The workshop aims to increase participant's awareness of the common emotions and their expressions, learning why is it important to know what you are feeling and how to manage it. Parent's affirmation is the most important above all else

UPDATES &



ANNOUNCEMENTS



CALL FOR RATIONS

A big THANK YOU to all who have answered our call for rations last month. However, our beneficiaries are still in need of the following items:

- 1) Pediasure 850g (Vanilla Flavor)
- 2) Cooking Oil (Halal)
- 3) Children Diapers (Drypers - XL/L Tape & Pants)

If you wish to make an in-kind donation, kindly please contact us at 6377 1789. Alternatively, you may click below to find out more about the items most demanded and required by our needy families.

TALENT DEVELOPMENT FUND

APPLICATIONS FOR 2018 ARE NOW CLOSED.

Our annual reimbursement scheme to recognize and nurture CRS beneficiaries' non-academic talents and interests by motivating and encouraging them to develop their capabilities.

UPCOMING EVENTS

Workshops
Bridge Programmes
CSR engagements

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