

# Celebrating Our Little Fighters

## Paediatric Brain and Solid Tumour Awareness Day 2019

Text by Lau Kin Mun and Candy Tan | Photos by Sim Xiangli and Harry Ng

If you were to ask anyone on the streets about cancer, few would be able to imagine what it means for a child to survive one.

Diagnosed with medulloblastoma at a tender age of six, 16-year-old Celeste struggled throughout her childhood. While other children of her age were enjoying school and play, she had to endure countless blood tests, hospital visits and surgeries, along with months of chemotherapy and radiotherapy. Even after her extensive course of treatment, her fight continues. Adjusting to school was particularly challenging; Celeste had to put in double the time and effort to catch up with the academic syllabus she had missed, while dealing with some of the psychomotor and cognitive side effects of treatment. Yet she never gave

up. "My parents were there to pray for me and remind me to stay strong," she said, as she recounted her fears of going under the knife. She also shared that when school got overwhelming, her father told her, "It is always easy to give up when things get tough, but you will never find out how much tougher you really are until you overcome these obstacles". The love and support from her family was what kept her and will continue to keep her going.

Celeste, along with 34 other brave little fighters, was part of a group of paediatric brain and solid tumour survivors who participated in the fifth Paediatric Brain and Solid Tumour Awareness (PBSTA) Day held on 23 March 2019 at the Marina Barrage. The PBSTA Day is an annual event organised

by Duke-NUS Medical School (Duke-NUS), in conjunction with KK Women's and Children's Hospital (KKH) and VIVA Foundation for Children with Cancer (VIVA Foundation).

In Singapore, brain tumour is the second most common childhood tumour. These tumours are associated with more rapid growth in childhood, which leads to long-term effects on growth and neurological development. Most of the tumours require aggressive treatment and some children face side effects, such as scars and hair loss, which they carry with them on their journeys. This makes the journey all the more difficult for our patients and their loved ones. Thus, our goal each year is to generate more awareness about paediatric brain and solid tumours, and to create an



avenue for affected patients and families to provide support for one another. For our fifth year, we brought the event out of KKH for the first time, and held a fun-filled carnival with games, food and performances at the Marina Barrage. This was a true game-changer for us – not only did we gather much positive feedback from the participants, but we also reached out to many members of the public to spread our message.

### Pre-event series

This year, we also expanded our pre-event outreach to champion more public awareness and understanding of paediatric brain and solid tumours. We had booths set up at KKH and Duke-NUS where the public could pen words of encouragement for our little fighters. Some messages received include: “You are a warrior, fight on!”, “Stay strong and happy”, and “A solid rock is not shaken by storm, keep fighting!” In addition, we formed a contingent of 18 medical students to take part in National Cancer Centre’s Run for Hope 2019 and had the privilege to run alongside two families and their little fighters. One of our classmates, Wong Xiang Yi (Class of 2021), even took part in a 100-km ultramarathon to help raise funds and awareness for our event.

Students from various tertiary institutions (Duke-NUS, Alice Lee Centre for Nursing Studies, Yale-NUS and NUS High School) were invited to join in our

celebration and affirmation of the little fighters’ efforts. Through our publicity efforts, including recruitment emails and an educational video on paediatric and solid brain tumours, we received an overwhelming 71 volunteer sign-ups. 46 volunteers were eventually selected to set up game booths and befriend our little heroes during the event. Through involving volunteers from various disciplines, including research and nursing, we hope to provide a platform for our volunteers to interact, and build rapport and lasting friendships among themselves.

### Line-up for the day

With the stage overlooking the waterfront and the carnival decorated with colourful balloons and streamers, attendees gathered at the Marina Barrage for a series of sharing and performances. Prof David Low Chyi Yeu commenced the carnival with a welcome speech and an introduction on paediatric tumours, before Celeste went on stage to courageously share her personal story.

We also had the privilege of having Ms Ng Mei Ting, a budding local singer-songwriter, perform an amazing line-up of originals and covers, and a duo band, Natalie and William, from Nanyang Technological University (NTU) who played popular songs including Paramore’s “Still Into You”, Elvis Presley’s “Can’t Help Falling in Love” and Rachel Platten’s “Fight Song”, which embodied the resilience and fighting spirits of

our little fighters. It was heart-warming to see the children and their families enjoying themselves and singing along to the performances.

Following the performances, the children and their families were welcomed to the carnival with goodie bags containing a DIY kite, thirst-quenching beverages and entertainment vouchers. They were also treated to delicious bento lunches, Milo drinks, Yakult beverages and Old Chang Kee snacks. The ever-familiar “Ice Cream Uncle” and his traditional ice-cream cart were also brought in for the event. With familiar Disney-themed tunes blasting from the AV system, the children were greeted with a variety of fun and engaging game booths, including activities like shooting quests and DIY handicraft magnets. Toys, donated by staff and students of Duke-NUS, could be redeemed by the children who participated in the games. Right next to the handicraft booth, we had our photo booth with friendly photographers who were ever ready to capture the bonds and friendships (along with wacky props!) formed during the activities via instant printouts. To top it all off, the children loved the balloon sculpting booth where they got to bring home their favourite lightsabres and balloon animals.

### Porsche joy ride

At 1.30 pm, our Guest of Honour, Ms Shulamite Khoo, Board of Directors of VIVA Foundation, gave an inspirational speech encouraging our little fighters.



Participants and volunteers then gathered for a group photograph before the official flag-off for the convoy of Porsche cars. Our little fighters could hardly contain their excitement as they looked for their driving companions whom they had met and spent time with earlier at the carnival. The little fighters even decorated personalised thank-you cards for the drivers as a token of their appreciation.

The convoy of cars, labelled with car decals displaying the event's logo, soon rode off with joyful little riders who waved at us shyly through the car windows. The event ended on a blissful note and it was indeed a fun-filled day full of love and laughter.

During her sharing, Celeste had closed with a touching message of solidarity.

"We are not alone, some of us are still in the hospital fighting, some of us might be back in school but facing different sets of challenges and the path we are taking could be different from other children, but we can still lead a fulfilling life knowing that we are on the same path together. That motivates me the most."

There is indeed much to learn from our little fighters, and we are privileged to have shared part of the journey with them. Let us too keep this spirit of trudging through the toughest times to stand triumphant at the top of our little hills one day, with hope, smiles and friends by our side.

### Our gratitude

We would like to thank our mentor, Prof David Low, who worked tirelessly with us to organise PBSTA Day 2019. We also thank the Guest of Honour, Ms Shulamite Khoo, and our little fighter Celeste for gracing the event with her family. Our thanks also go out to the volunteers who took time out of their busy schedules to support the morning's activities. Last but not least, a big thank you to our various partners and sponsors from Duke-NUS, KKH, SMA Charity Fund, Viva Foundation, Brain Tumour Society (Singapore), National Neuroscience Institute, Porsche Club Singapore, Pirelli, Exquisite Technique, Yakult, Science Centre Singapore and Gardens by the Bay for making PBSTA Day 2019 a truly meaningful and fulfilling event for our little fighters and their families. ♦

### Did You Know?

- + Brain and solid tumours make up 55% of paediatric cancers in Singapore.
- + About 40 to 50 operations are carried out on children with brain tumours at restructured hospitals every year.
- + Brain tumours are the leading cause of death in childhood cancers worldwide – 36.1% and 33.3% of cancer deaths respectively in male and female children in Singapore every year.
- + The common types of solid tumours are neuroblastoma, rhabdomyosarcoma, retinoblastoma, Wilms' tumour, osteosarcoma and Ewing sarcoma.
- + Treatment depends on the type, severity and symptoms of the tumour. Some options include chemotherapy, radiotherapy and surgery. However, research on brain and solid tumours has lagged behind, leading to lower success rates in their treatments compared to leukaemia.

### To find out more

- + VIVA Foundation is a Singapore-based charity which focuses on promoting research and medical care for children with cancer. Visit them at <http://www.viva.sg>.
- + Brain Tumour Society (Singapore) is a non-profit society which provides moral and resource support to brain tumour patients and their caregivers. Check out their website at <https://www.braintumoursociety.org.sg>.
- + You can also find out more about PBSTA Day on our Facebook page, <https://www.facebook.com/pbsta2019>.

### Legend

1. Our contingent at the National Cancer Centre's Run for Hope
2. Little fighters taking part in a kite-making activity
3. Sharing a light-hearted moment at the event
4. The PBSTA Day 2019 organising committee

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Kin Mun and Candy are second year medical students from Duke-NUS Medical School Class of 2021 and are the co-heads of publicity for PBSTA Day 2019.

