

## **Proposal for funding**

## Hong Kong Cancer Fund's

# "Rainbow Club" Programme

May 2020



#### 1. About Hong Kong Cancer Fund

Established in 1987, Hong Kong Cancer fund is Hong Kong's largest cancer support organization, providing free information and professional support to anyone living with or affected by cancer. With a network spanning the hospital, the community and the home our mission is to ensure no one faces cancer alone. Receiving no money from the Government or Community Chest, Hong Kong Cancer Fund relies solely on public generosity to make life better for anyone touched by cancer.

#### 2. Introduction

The Rainbow Club was started in November 2010. It is an extension of our care and support services to all children aged 17 years old or below whose family members are affected by cancer, ensuring children are well cared for and supported in coping with changes in the family as a result of cancer, helping parents and children to communicate on cancer and its impact, and ultimately minimize their emotion distress. The programme is now available in Cancer Fund's Support Centres in the community.

Cancer affects the entire family. Cancer is not an easy subject to talk about and many parents avoid the topic in fear that they will scare their children, making things worse. However, when someone in the family is diagnosed with cancer and it's not talked about, a child's fear, anxiety or sadness will only increase.

They could feel lonely, depressed and frustrated. Children need to have cancer explained to them by professionals in a language they can understand and receive support to cope, just like adults. It is

important that children and adolescents know that they will have ample opportunities for questions, discussion, clarification, and reflection, and the situation is not caused by their misbehavior or fault.

"I was totally lost when I was diagnosed with stage 2 breast cancer. I was struggling how to explain my situation and the effects of cancer treatment to my son. I just thought of death but nothing at that moment and I was not interested in anything anymore. I avoided my son as much as possible so that he would not be affected by my negative emotion. However, I underestimated the sensitivity of a 4-year-old boy to the changes around him. He suddenly became very unreasonable and bad-tempered. He tried to seek everyone's attention with his misbehavior and even hit his classmates at school. He was afraid that I was no longer love him and left him very soon. I felt so guilty about leaving my son under fear and helpless just because of my cowardice. Fortunately, I learnt about Cancer Fund's Rainbow Club which has led us out of the dark. Cancer Fund's staff taught me and my husband how to communicate with my son about my situation with the language that he would understand. My son was also able to express his inner feeling and thoughts through different ways such as play therapy and art therapy. Our whole family gradually regain hope and we have developed a positive mindset to cope with cancer together. I am so happy that my lovely boy comes back again."

## Ms. Ko (age 34), Survivor of breast cancer

According to statistics, it is estimated that about 2,000 children may be living with a parent with cancer in Hong Kong<sup>1</sup> (Hong Kong Cancer Registry 2017 & Census and Statistics Department 2017).

Since its inception in 2011, the Rainbow Club has helped over a thousand children with a close family member touched by cancer. With some of the children entering adulthood in the past few years, the actual number of children aged below 18 is now 778. In 2018/19 we delivered a total of 52 programmes for 864 users (including parents and children).

## 3. Objectives of The Rainbow Club :

- To reduce psychological distress of children and their adult caregivers who are diagnosed with cancer at various points of the cancer journey
- To assist the family to restore normal functioning by providing resources, communication opportunities, and professional support
- Develop the resilience of children and parents
- Build social connection and promote understanding of the needs of these children in the community

<sup>&</sup>lt;sup>1</sup> According to the statistics released by the Hong Kong Cancer Registry of Hospital Authority, there are 15,566 newly diagnosed cancer patients were at the age of 15 and 64 years old. This is the age range that many individuals may have dependent children. With reference to the statistics from Census and Statistics Department, the child dependency ratio in 2017 was 158 (persons aged under 15) per 1,000 aged between 15 and 64. From these figures, it is estimated that the 15,566 newly diagnosed cancer patients may have around 2,459 dependent children.

## 4. Programmme Descriptions

## I. For the Children

Children respond differently when a family member is diagnosed. For example, children at pre-school age might not be able to fully understand the concept of cancer, death and dying. Yet, they are the most sensitive to the changes in their caring routine and environment which determine their sense of security.

School age children might be able to think logically. They are able to realize the consequences of cancer. They gain a sense of problem solving but they might feel powerless in the face of the diagnosis. Preadolescent children develop more complicated thoughts and feelings about cancer.

## Age-appropriate programmes for coping and emotional expression

Young children may have difficulties in expressing their feelings and may need help to find the right words to articulate their feelings and thoughts. Through **Play Therapy** we explain how their parent may need to go to the hospital. We provide information about cancer and the appearance and behavior that may occur due to medication and treatment so that they can cope more effectively with the situation.

Our play therapist will use various media to communicate with the child, these can include, storytelling, puppet play, drama, music, sand play, painting etc to help children find ways to express their inner feelings and emotions. Our therapist will be ready to answer question such as 'Did I cause my mum/dads cancer?'; 'Will I get cancer now?' or 'Will my mum/dad die?'

For the older children and adolescents we use **Creative Writing** and **Art Therapy** to help facilitate their emotional expression and encourage discovery and acceptance. Depending on the individual needs, the therapists will combine several techniques together to provide the most appropriate support for the child. This will include art forms such as music, movement, play, psychodrama, sculpture, painting, and drawing.

Our clinical psychologist is on hand for our children to talk to regarding their fears for relapse or how to cope within the family environment.





"Mommy told me that daddy has cancer. I am so sad that he cannot play football with me and he looks so pale and week. I am also very afraid that daddy will leave us soon. I see mommy keeps crying at her bedroom. I wish to help mommy and daddy but I don't know what I can do to bring us back to those happy days. Sometimes, I want to stay at school rather than going home as I don't want to see mommy cries. Mommy takes me to Cancer Fund's Support Centre earlier to join the activities of Rainbow Club. A big sister often plays different games with me which I find very interesting. I can also talk to the big sister my sad feeling secretly when I don't want to tell mommy. All of these have made me feel better than before. I just hope mommy could let me go to the Centre more often." **Noah (age 7), son of a nasopharyngeal cancer patient** 

#### Peer support

Peers provide an important source of support as they learn to listen to, encourage and rely on each other through difficult times. The peer support groups at Rainbow Club allow children to share their experience with those facing similar situations, and they can build rapport, trust and draw strength from each other.

In addition to the traditional face-to-face peer support groups, we also developed **web-based peer support** for adolescents, and through a closed Facebook group (for Rainbow Club members only) and other social media platforms (such as Kakao) they connect and share their emotions. These groups are monitored by our staff and follow up discussions with other specialists such as nurses or therapists will be arranged if required.

#### II. For the Parents

Many parents are unsure how, if or when to talk to their children about a cancer diagnosis. They wish to shield their child from any fear or upset they may cause and try to 'hide' the diagnosis. But children are very perceptive and sense the changes around them. Young children may make the assumption that the cause of the change to their family, or their parent's illness, is their fault.

Many medications and treatments have major side effects including hair loss, nausea and tiredness. Parents may not be able to keep to the normal daily routine that children rely on for mental security. They may also struggle with feelings of guilt and are worried about missing important milestones of their children.

#### **One-on-one Counselling & Family Workshops**

At the Cancer Fund we are here to help guide parents on how to approach the subject of cancer with their children. We have one-on-one counseling session with the parents to talk through their child's behavior. If requested we can have follow up meetings where we can help the parent share the diagnosis with the children. We also hold family workshops designed to improve the relationships and communications

between the parents and children, in a safe and secure environment where children can open up about their concerns.

## Learning to cope at home



For families with younger children we will introduce play-based programmes to the parents if their children are showing some behavioral and emotional issues. Parents learn new skills on how to provide opportunities for children to ask questions and respond more effectively to their children's needs at home. In turn, children learn that they can always count on their parents for love and acceptance.

For families with adolescents, we seek to improve interaction so that older children can be involved in ways contributing to the parents' well-being, such as accompanying them for medical appointments or making plans to do fun things together. Through working with school counsellors and parents, we help children maintain their normal daily routines, be engaged in activities they enjoy and live positively.

#### **Outings and Family Gatherings**

In addition we organize various family outings and gatherings not only to take away the stress of cancer but also to build long-lasting memories that everyone will cherish.

#### III. Bereavement care

Losing a loved one to cancer is traumatic for all of the family and children may respond in different ways. Younger children may ask 'Why did mum/dad die?'; 'Did I do something wrong' or 'If I die, will I be able to join my mum/dad in heaven?' Through counselling, our bereavement specialists are here to help guide children through this sensitive and often confusing time.

We are also here for all of the family, especially when a husband or wife who has lost their partner. We offer one-on-one support to help them through the grieving process. A parent who has lost their partner and has children dependent on them often feels guilty about showing their emotions assuming that they have to be strong in front of the children. They don't know if they should talk to their children about their loss or memories of the loved one. We help the parent deal with their emotions and grief while supporting them to continue with their parenting roles, optimizing communication among the family and strengthening mutual support.

In addition to our centre-based bereavement service, we have also been collaborating with the EQ Ambassador Society at Tuen Mun Hospital since 2010. This is a child and family bereavement service to help children and family overcome the pain with the loss of a parent. Through counselling and peer support groups, the service eases the sense of loneliness faced by bereaved children. They are also educated on the topics of life and death through fun and creative ways using drama and art.

"We are so glad to know the free services offered by Cancer Fund. Their professional services have helped me and my daughter to sail through the most difficult time when we lost my husband. I can't imagine how we would be if we did not meet Cancer Fund.

My husband's appearance changed significantly since he received cancer treatment. He became so weak and he almost lost all of his hair. He even did not have the energy to talk and walk. My daughter Zoe could not accept the sudden change of his father. She felt so scared that she refused to stay with her father. She also had nightmares and became bad-tempered afterwards. Her teacher said she behaved so differently than before but she did not want to talk to anyone. Zoe's situation became even worse when my husband passed away. She often screamed and cried during mid-night and she thought her father's death was due to her fault. I was so depressed and frustrated as I had to suffer from the loss of my husband and I had to deal with Zoe's emotional distress alone at the same time. I had thought of committing suicide to escape from all these problems. However, I gave up soon when I thought of Zoe. Our social worker then introduced the bereavement care provided by Cancer Fund's Rainbow Club. Zoe is allowed to express her negative emotions through Art Therapy and I am able to vent my depression through one-to-one counselling service. Zoe's emotion has gradually become more stable and her misbehavior is also improved. She now understands the bonding among us would not change though her father is not here and she no longer blames herself for the death of her father. We are so grateful for the help from Cancer Fund which truly changes our lives"

Mrs Hui (age 42), Widow of a lung cancer patient

## IV. Outreach Programme

## School programme for teachers and social workers

In addition to centre-based counselling services, it will bring additional benefits if there is a supportive school environment to help families touched by cancer. We plan to reach out to 10 schools (primary and secondary) to discuss with teachers and social workers on how to identify children who may be affected by their parent's cancer. We will discuss how to help with behavioral changes and how to support the children and their family throughout the cancer journey.

#### 5. Projected number of beneficiaries in a year

- Current children under the Rainbow Club : 778
- Projected new members : 200 children
- Projected new parents : 200
- 10 schools (primary and secondary schools) with 50 teachers and school counsellors

## 6. Programme staff

It is crucial that we provide a professionally trained team for these programmes and sessions, including clinical psychologist, social workers, art and play therapists. With public awareness and knowledge about cancer we are finding more and more people are seeking help and receiving the medical intervention they require. With the increasing number of families being touch by cancer the service demand will continue to grow as will the need for more professional support.

## 7. Annual operating costs

As we do not receive any funding from the government or Community Chest, any amount of sponsorship for our operating cost will help ensure the continuity of our vital support for children through the Rainbow Club. Your generosity will make a huge difference to the children and families touched by cancer.

To sustain this meaningful initiatives, we are seeking annual funding of <u>HK\$2,000,000</u> for Rainbow Club. It is mainly used to support the staffing cost for professional staff, programme and operation cost and the funding for EQ Ambassador Programme at Tuen Mun Hospital.