

MAKE BLOOD CANCER VISIBLE

#MAKEBLOODCANCERVISIBLE

Asia Pacific Report

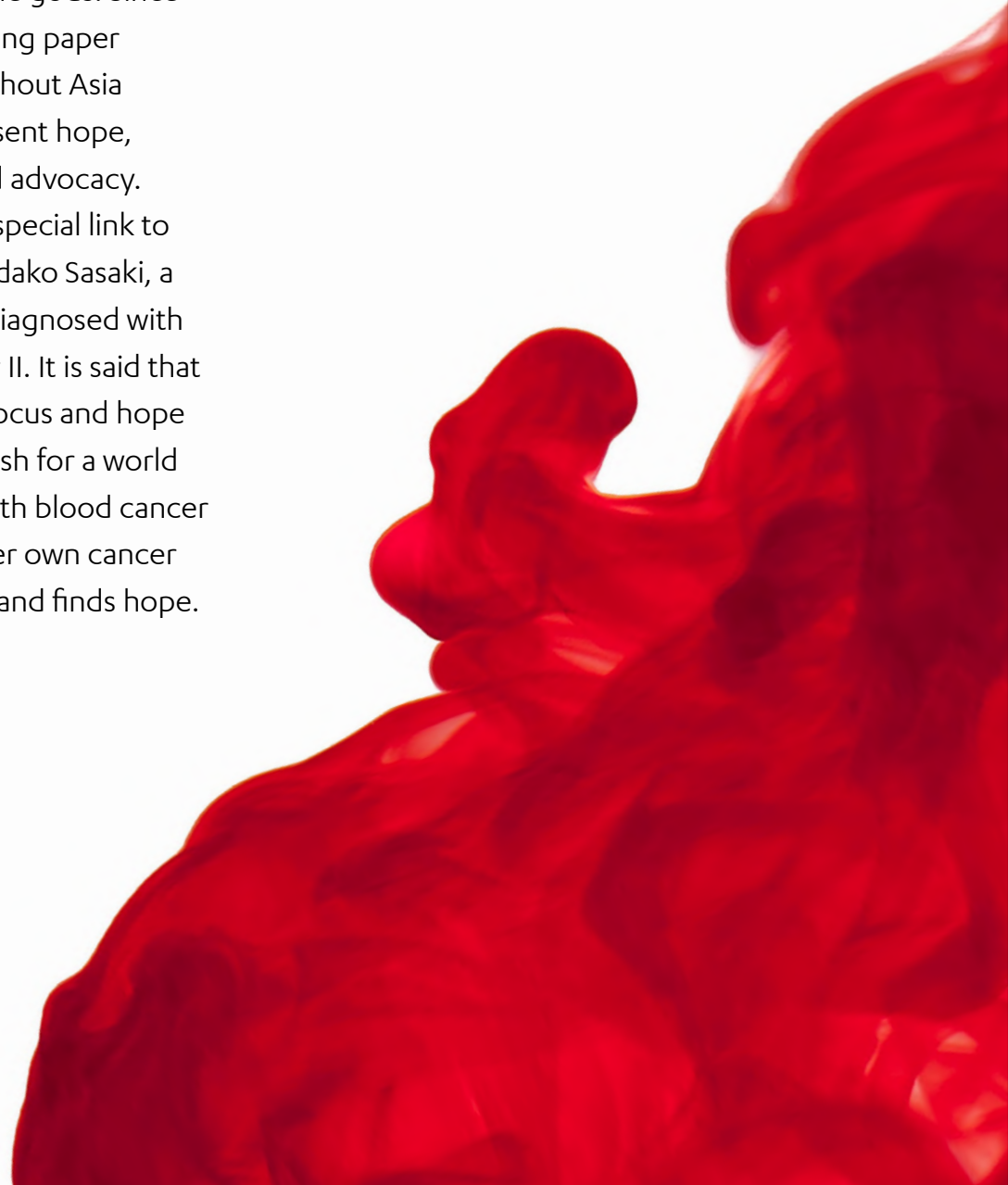


janssen  Oncology

PHARMACEUTICAL COMPANIES OF *Johnson & Johnson*

About the Cover Design

The practice of senbazuru originated in Japan. It was believed that a person who folded 1,000 paper cranes would be granted a wish from the gods. Since then, the practice of folding paper cranes has spread throughout Asia Pacific and used to represent hope, the community voice and advocacy. Paper cranes also have a special link to blood cancer through Sadako Sasaki, a young woman who was diagnosed with leukemia after World War II. It is said that folding cranes gave her focus and hope during treatments. We wish for a world where every individual with blood cancer is empowered in his or her own cancer journey, feels supported and finds hope.

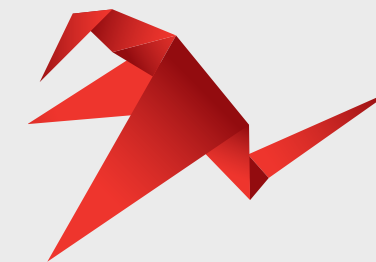


Foreword by

Weng Ho Chow,

Vice President, Asia Pacific Medical Affairs,
Janssen Asia Pacific

“Blood cancers make up seven percent of all cancers worldwide, yet their disparate nature leads to a lack of public awareness. We must work together to improve the understanding and public profile of blood cancer in our communities.”



Our aspiration should be to transform blood cancer into a preventable, chronic or even curable disease by delivering innovative treatment options to patients who need them most. Of course, patients require more than treatment and care, they also need information and support.

At Janssen, we have a strong legacy across Asia Pacific in leading innovation in the treatment of blood cancers by developing and providing transformational treatments that prolong and enhance lives – however we want to do more.

It is this passion to do more that has sparked the Make Blood Cancer Visible initiative in this region and around the world. It is our hope that the stories shared in this report raise awareness and understanding, so those living with blood cancers no longer feel ‘invisible’ but empowered, and ultimately bring us one step closer to our aspiration of making blood cancer a disease of the past.

Opening by

Mei Ching Ong,

Region Head for Asia Pacific,
The Max Foundation

What We Believe

Asia Pacific is a region of diversity. We see this in its healthcare systems, its socio-economics, beliefs and practices, but also in how cancer as a condition is perceived and addressed. Blood cancer in particular remains a big challenge faced by our community, especially in understanding the disease, associated stigma, available resources, diagnostics, monitoring and treatment.

As I reflect on this beautiful collection of stories that spotlights blood cancer survivors from across Asia, I cannot help but think about how The Max Foundation came to be. Maximiliano “Max” Rivarola lived with chronic myeloid leukemia (CML) for three years before passing away in 1991 at the age of 17. Our organization was established in his honor in 1997. The work that we do on behalf of patients with all types of blood cancer is inspired by this legacy.

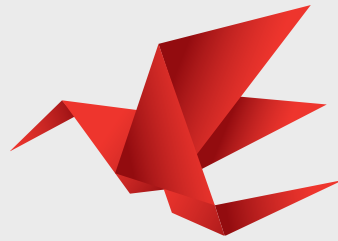
Reading through the perceptions of blood cancers in China and Japan, I am reminded of how much more work there is to do, not only for patients in these two countries, but across all of Asia Pacific. Educating and raising more awareness around these diseases to make them more visible is critical as we work towards better access to treatment.

It is the goal of The Max Foundation to continue working with various stakeholders across all backgrounds. From individual caregivers to policy makers, oncology institutions to healthcare professionals and even non-healthcare organizations, we all need to work together in building a better future where all people facing blood cancer live with dignity and hope.

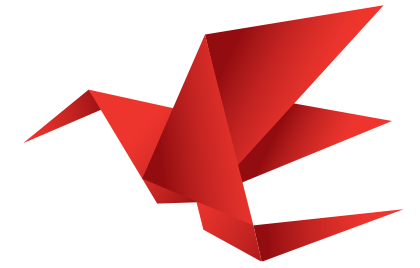
“With access to treatment, a patient is able to live now. With access to support and education, a patient is able to live well, and with capability building, a patient is able to live for the future.”

Our experience has taught us that these three aspects are key for each and every blood cancer survivor.

This book, which brings to you facts, figures, and stories from Asia Pacific, helps to make blood cancer visible, and I hope inspires you and others to join us in our work on behalf of patients in the region.



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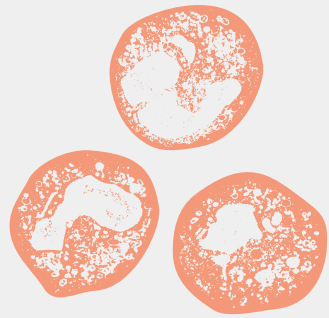


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The facts

Blood cancer is not one but 140 different cancers that affect the blood, bone marrow and lymphatic system.¹

Blood cancers fall into **three main** categories:



Leukemia

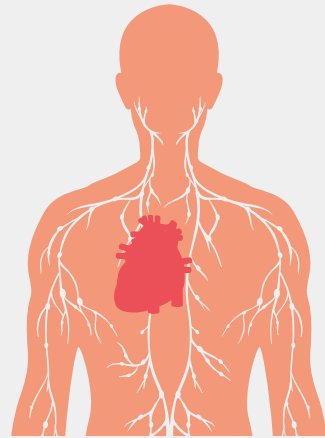
A cancer of the white blood cells

Abnormal white blood cells, usually responsible for fighting infections, block up the bone marrow. They then move quickly into the blood and spread to other areas of the body.

1 in 3 cancers in children in industrialized countries and territories is a leukemia.²

Types of leukemia include:

- Chronic lymphocytic leukemia (CLL)
- Chronic myeloid leukemia (CML)
- Acute lymphocytic leukemia (ALL)
- Acute myeloid leukemia (AML)



Lymphoma

A cancer that starts in the lymphatic system

Abnormal white blood cells block up the lymphatic system, an important part of the immune system.

Types of lymphoma include:

- Diffuse large B-cell lymphoma (DLBCL)
- Mantle cell lymphoma (MCL)
- Follicular lymphoma (FL)
- Marginal zone lymphoma (MZL)
- Lymphoplasmacytic lymphoma (LL)
- Mucosa-associated lymphoid tissue lymphoma (MALT)



Myeloma

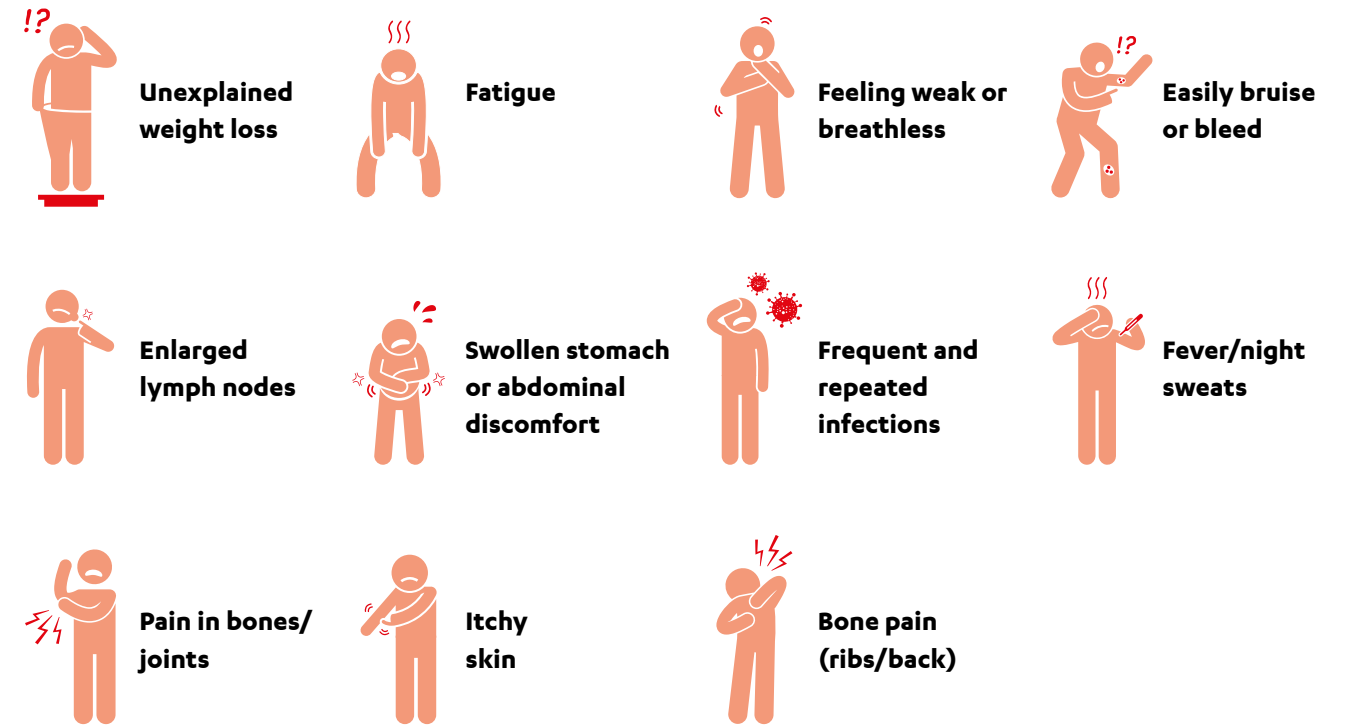
A cancer of plasma cells in the bone marrow

Bone marrow is blocked up by abnormal plasma cells, usually responsible for making antibodies and responding to an infection.

138,509 new cases of multiple myeloma were recorded globally in 2016.³

Blood cancer symptoms⁴

May vary but commonly include:



Blood cancer risk factors⁵



Blood cancer in **Asia Pacific**

Data on blood cancer incidence and survival rates is limited in Asia Pacific.

The context

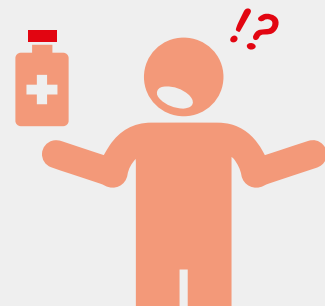
- Disease progression for Southeast Asian patients diagnosed with chronic lymphocytic leukemia (CLL) is faster than in Caucasians.⁶
- The incidence of lymphoma in Asia is increasing, mirroring the trend of Caucasian data at a lower rate.⁷
- By world regions, Australasia has the highest age-standardized incidence rate of multiple myeloma, followed by high-income North America and Western Europe.³

Misconceptions about blood cancer are common in the region

Diagnosis equates a “death sentence” as blood cancer is perceived to be **incurable**.⁸



Patients and survivors will not be able to regain quality of life.



The causes of blood cancer are not well understood by the public. For example, some incorrectly think that **anemia** is a cause of cancer.⁸



Like other cancers, blood cancer is **perceived to be contagious**.⁹

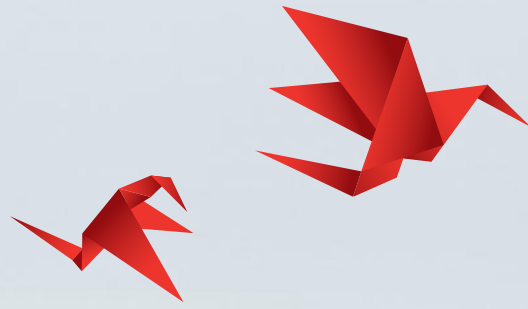


Asia Pacific Insights

There is still much work to be done in **educating around symptoms, support, and survival for blood cancer in Asia Pacific.**

Australia

Blood Cancer Insights



The facts

In 2012, blood cancer was the **third** biggest cause of cancer death across Australia, claiming more lives than breast or prostate cancer.¹⁰

While more children are surviving the disease,

almost half of adult blood cancer patients will lose their lives.¹¹

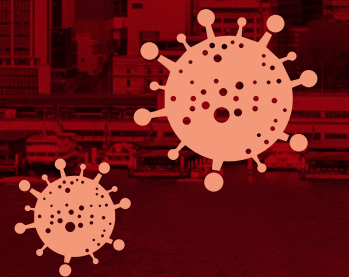


In total, blood cancer accounts for around

10% of all cancers diagnosed each year.¹¹



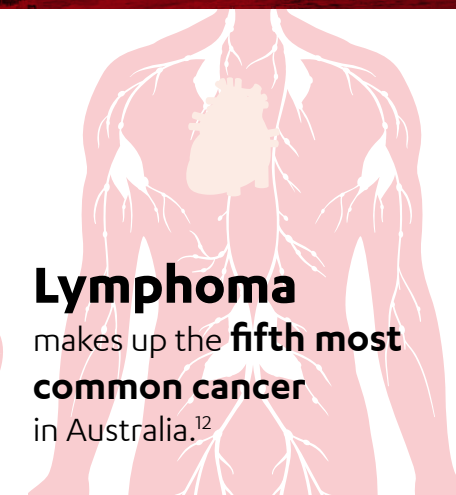
60,000 Australians currently live with a blood cancer. Around **35** Australians are diagnosed each day with a blood cancer.¹¹



In 2017, there were **11,923** combined new cases of leukemia, lymphoma and myeloma in Australia.¹²



Lymphoma makes up the **fifth most common cancer** in Australia.¹²



There are around **1,600** new diagnoses and **900** deaths related to **multiple myeloma** annually in Australia.¹²





Melbourne, Victoria

Mummy's magic medicine

Deborah Sims, 44

Chronic lymphocytic leukemia (CLL)

The hardest thing I've ever had to do was kiss my three young children goodbye in August 2015 and move to London – hopeful of getting on a clinical trial. Truth is, I didn't know if I'd come back.

I was diagnosed with an aggressive form of CLL/SLL in December 2011. Just days before Christmas that year, I had taken my then two-year-old daughter to the doctor, where by chance my general practitioner (GP) asked about my health. I had seen a different GP about a lump in my neck earlier that year. When I got the "all clear" from an ultrasound and blood test, I just got on with my busy life, forgetting about the follow-up due six weeks later.

When my GP said, "I see you came in six months ago, is the lump still there?" I said, "yes and there are a few more too." She examined me, gave me a hug, and asked if I had private health insurance. She then encouraged me to meet with a hematologist. The next day I had a lymph node biopsy and was told I had CLL the following week. I was just 38.

I had the worst Christmas of my life. I mourned myself for two weeks and went into my shell. I was put on 'watch and wait' and began my own in-depth research into CLL while continuing to work full-time.

As a journalist, I needed information. I joined forums, subscribed to medical journals, and sought a number of specialists for second opinions. When it came to available treatment options, whether it was a stem cell transplant, clinical trials, new drugs or chemotherapy, I would always assess each risk to give myself the best chance to see my children grow up.

By October 2012, I was really sick and very tired. I couldn't schedule afternoon meetings at work. It was in January 2013 that I started on a chemotherapy and immunotherapy regimen – the standard of care in Australia – even though with my markers, my doctors knew it wouldn't hold the disease at bay for very long.

While I responded well to the treatment, I wished I had listened to my doctors and started my treatment earlier. Three months in, it was suggested that I stop my regimen to avoid the extra toxicity. I returned to 'watch and wait,' with three-monthly bone marrow biopsies, but at six months it was evident my disease was progressing and my specialist talked about when I might have a transplant. A transplant was earmarked for early 2015,

but I first needed more treatment to reduce the bulky disease.

Inspired by an Australian businessman's success with a new immunotherapy treating his melanoma, I attended a patient conference on CLL clinical trials in the U.S. in April 2015 where I consulted an international CLL expert. He said: "You should not have a transplant. We are on the verge of a cure. We just have to work out what the best drug is. You need something to buy yourself some time." It was further fortuitous that one of the conference speakers from the UK, sat next to me. We chatted and he told me about a clinical trial in London that would be the best possible treatment for me at that stage.

I asked one of my Australian specialists: "If you were me, what would you do?" and he answered – "I'd get on a plane to London."

My best chance was a trial 10,000 miles away. With a shot at a long remission and possibly a cure, I dipped back into my superannuation fund and set off.

In September 2015, when I heard the great news that I was on the trial, I was so excited. It felt like I'd won the lottery! My three children, then aged 11, nine, and six, and their father arrived in London as the trial began for nine weeks to coincide with me starting what they called "mummy's magic medicine."

This was a very easy therapy to tolerate. I had no side-effects from the combination treatment and a CT scan in February 2016 showed I was in partial remission. My blood work was fantastic.

"I was working again and going out. It had given me my life back again."



I'm now 28 months in on the trial and my latest bone marrow biopsy showed that I still have no detectable disease. My children are now 13, 11 and 8. And I've outlived my prognosis by a year.



Sydney, New South Wales

A “new normal” made possible

Rob Domone, 68

Chronic lymphocytic leukemia (CLL)

I was first diagnosed with CLL in April 2011, after seeing my GP due to a severe ear-ache. She ordered a full blood count and the report mentioned a slightly high white blood count, with a note: ‘CLL?’ She called me in and explained it was slow-moving and treatable.

I’d never heard of CLL and was very surprised. There was no history of CLL in my family. Both my parents lived to about 90, and I’d always been pretty healthy and fit. My wife, who has worked as a medical librarian, helped me research CLL, and we visited a specialist who suggested I take the standard approach at the time – ‘watch and wait’. I had no obvious symptoms then, had my blood checked every three months and continued to work in the IT department at a Sydney hospital. I decided to retire in November 2011.

Eighteen months after my initial diagnosis, my white blood cell count had increased while other blood counts were dropping, and I had a swollen lymph node in my left groin. It was then that my specialist decided it was time to look at treatment.

A bone marrow biopsy and FISH² test showed that I had the 17p-deletion genetic mutation. This aggressive form of the disease occurs in around 7% of people with untreated CLL and for this group, the standard chemotherapy and immunotherapy regimen was less effective.

I had no idea there were different types of CLL, what 17p-deletion meant, or that there were clinical trials. I started looking on the internet to see what drugs existed and what trials were available in Australia. I wasn’t too happy that none were available here, so I had to just wait and see and maybe get on a trial overseas.

By November 2012, the node in my groin had grown to the size of a grapefruit; my left leg had become swollen and my white blood cell count was 70 (normal: 4-11). My specialist suggested that I try the chemotherapy and immunotherapy regimen because I had no alternative.

This was when I contacted the Leukemia Foundation seeking information, and learned about a doctor from a cancer center in Melbourne. It just so happened that this doctor was looking for patients with 17p-deletion CLL, who had tried the chemotherapy and immunotherapy regimen and failed, to join a trial for targeted therapy. I wasn’t eligible for the trial as I had yet to try

chemotherapy and immunotherapy. But at least there was a trial and I had some hope!

I had my first chemotherapy and immunotherapy treatment in mid-December 2012. After my second cycle a month later, I was hospitalized with a fever and a zero-neutrophil count. This was a particularly worrying time for my wife, our two daughters and families. Over the next 19 days I was in hospital and lost 10kg. It took a while to find out what I had. I was eventually treated for a type of fungal pneumonia.

By February, the node in my groin, which had only reduced slightly during treatment, had returned to its original size. I sent my latest test results to the doctor in Melbourne and was eventually one of only five people in Australia and 101 across the world to be enrolled in the three-year clinical trial.

Three weeks after starting the trial, all my enlarged lymph nodes had disappeared, and within a few months my bloods were all back to within the normal range. It was brilliant. These targeted therapies are the way of the future, particularly for older people because they’re much kinder on the body and have less side-effects. I’d really like to see them fast-tracked so they are available to everybody more quickly.

“I’m sailing again, back at the gym, can work in the garden and do a few things around the house. I just have to do a bit at a time. This is the ‘new normal’.”



I don’t have as much energy as I used to have. I get tired and can easily pick up infections, which are also harder to fight off. This is because my B-cells don’t work and is typical of CLL.

When I can, I join the Leukemia Foundation’s monthly blood cancer support group at the local hospital.

March 2018 marks five years on my treatment and life for me is pretty much back to normal.



Coffs Harbor, New South Wales

More treatment options provide hope

Dave Wilson, 64
Multiple myeloma



I dosed up on paracetamol to overcome the exorbitant pain I was experiencing, in order to walk my daughter down the wedding aisle in December 2016. Never did I think my lower back pain was related to the smoldering myeloma I had been diagnosed with back in February 2015.

Having had a back problem 20 years earlier, I just thought I'd hurt my back lifting too much steel when helping my son build a large shed in October 2016. But we finished the shed and my bad back got worse.

After our daughter's wedding, my wife insisted I see my GP, and next morning, my hematologist called and said: "Come straight in, that's your myeloma kicking off!"

I wish I had done more research and recognized the back pain as active myeloma.

Two years earlier, after my retirement, my wife and I, packed up and embarked on a road trip to see Australia. I came home to a letter from the Red Cross – I'd donated blood for the previous 15 years. It said: 'Please take this letter to your doctor, we don't need to collect blood from you anymore.' I knew this was not a good sign. I visited my GP who explained how paraprotein, which was indicative of myeloma, had been detected in my previous blood donation.

"I'd just retired and suddenly I had blood cancer."



I was referred to a hematologist who explained that I was at a very early stage of asymptomatic myeloma, or monoclonal gammopathy of undetermined significance (MGUS). I had evidence of myeloma in my blood, but no symptoms. Some people can be like that for six months and others can go 10 or 15 years asymptotically.

My hematologist said "go and enjoy your travels" but wanted to do a blood test every three months to monitor my paraprotein levels. As one of the major symptoms was bone pain, I had to also let her know immediately if I suffered aches and pains in my thigh bones.

I was asymptomatic for about two years and led a normal life. It was frustrating to be fit and healthy one day and the next day to be told you've got blood cancer – but you don't feel any different! It was therefore easy to put this

cancer business right out of your head. It wasn't until the symptoms really set in that I realized the need to know a lot more about myeloma. That's when I discovered a Leukemia Foundation publication called Myeloma, a guide for patients and families, which explained the range of therapies being used worldwide.

I was put on a chemotherapy drug, and was pleased that I was on what was considered as best practice. It was evident after three months however that the treatment wasn't managing the myeloma at the expected rate, so the doctors changed my treatment in April of that year.

This process was harder on my wife than on me. I'm a very positive, glass 120% full sort of person, but it upset my wife considerably that I was responding poorly to the drug.

Thankfully, the Leukemia Foundation's closed Facebook myeloma network group was a great source of support for my wife and other caregivers. Members would share their experiences and respond to her questions within 24 to 48 hours. One in particular said, 'Don't worry, I didn't respond either and I went on to another treatment and it worked really well for me.'

A month into the new treatment, my paraprotein level dropped more than it had over the previous three months, and continued to drop consistently. To be considered for a stem cell transplant however, my paraprotein had to be well under 15. It was three at the time of my transplant in November that year. I chose to have my transplant in Brisbane, so my daughter, who lives at Toowoomba and my son, who lives at Warwick, could visit during and after the procedure.

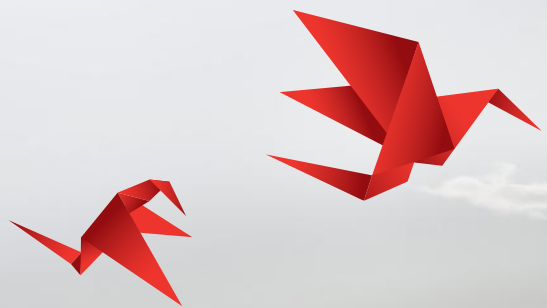
I've been very fortunate. My wife and I have been able to do a bit of travelling and visit our children for longer periods.

My hematologist said, "If you were presented to me when I started my career, I'd have given you two years. Today there are multiple drugs coming out by the year that give patients more options for treatment. If you don't respond to one, there's something else, and if you don't respond to that there are more and more fallback lines now."

My transplant hematologist hopes I'll get a 10-year remission and said that in a decade the science of treatment will be totally different. I hope he is right and if it does come back, I know now there are more treatment options.

China

Blood Cancer Insights



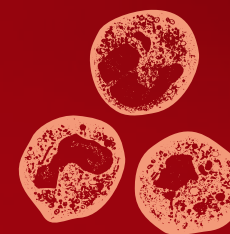
The facts

Cancer has been the leading cause of death in China since 2010.¹³

Leukemia is the **ninth** leading cause of cancer death in

China. As of 2012, the annual mortality rate of leukemia is

3.85/100,000 people.¹⁴



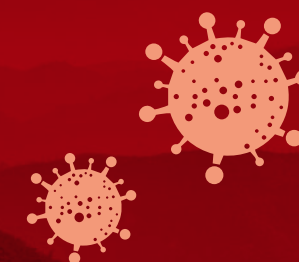
Lymphoma is the **top ten** leading cause of cancer death in China. As of

2012, the annual mortality rate of lymphoma is

3.18/100,000 people.¹⁴



When compared to the United States, China had a **higher incidence of leukemia**, and a lower incidence of Hodgkin lymphoma, non-Hodgkin lymphoma and multiple myeloma in 2008.¹⁵



The estimated incidence rate of multiple myeloma is **1-4/100,000 people per year** in China.¹⁶



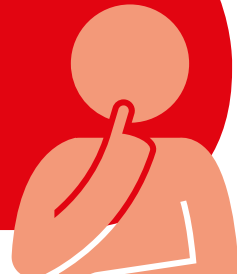
From 2001 to 2011, there has been an upward trend in age-standardized mortality rates for four of the 10 most common cancers in men (**colorectum, pancreas, prostate, and leukemia**).¹⁷



In 2017, Janssen Asia Pacific undertook a study in China asking 2,000 members of the general population about blood cancer. The study revealed the need for more work in making blood cancer visible. The results are featured in the pages that follow.

China Study Insights

In China, understanding and perception of blood cancer is surface-level.



1 in 2 respondents either **don't know anything** about blood cancer or **only know it by name.**

70% of respondents were **unable to define** blood cancer

1 in 4 respondents **could not name** a single symptom of blood cancer

With younger generations and lower income groups, blood cancer is even less understood.



Nearly half of the **younger generation** could not define blood cancer



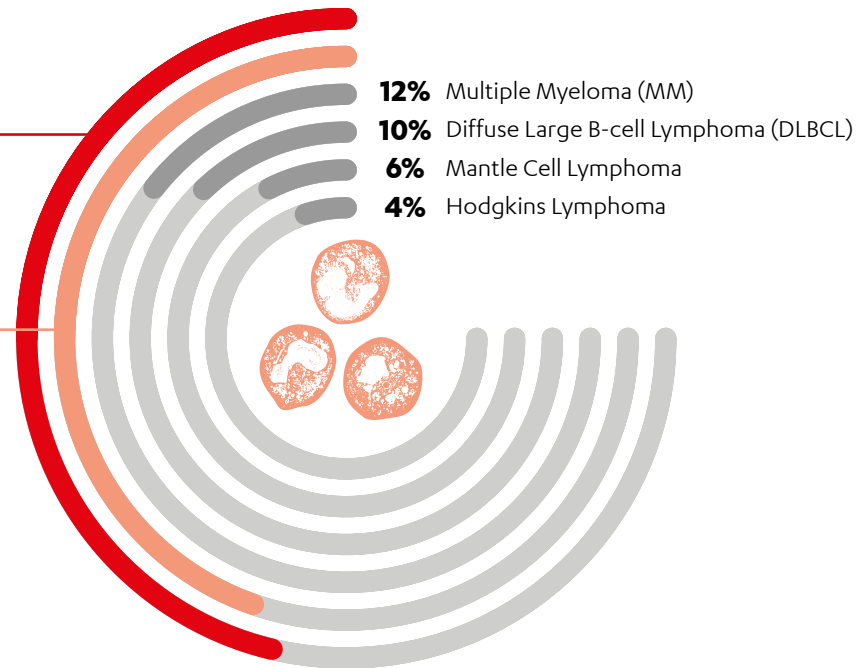
43% of the **lowest income class** in China could not define blood cancer

An obstacle to understanding blood cancer is that it is typically viewed as only one disease.

Most respondents in China only identified leukemia as a type of blood cancer.

39% of respondents consider **Chronic Lymphocytic Leukemia (CLL)** as a type of blood cancer while

37% consider **Acute Myeloid Leukemia (AML)** as a type of blood cancer



Low awareness can lead to a number of fears and misconceptions about the disease.



Low Survival Rates

89% of respondents **don't think or don't know** if a patient diagnosed with blood cancer has a good chance of survival



Poor Quality of Life

80% **don't know** if patients can achieve quality of life with proper medications

Blood cancer patients are seen as least able to commit to physically perform daily work tasks, work long hours and manage family commitment without challenge.*



57%

Physically perform routine, daily work tasks



56%

Work long hours or weekends if needed



56%

Manage family commitment without challenge



1 in 2 say that someone with blood cancer will be **asked to take time off of work or leave their position**

Limited understanding of the treatment options can lead to fears and misconceptions.



Nearly 3 out of 4 respondents view chemotherapy and radiotherapy with fear, saying that patients will **experience "serious side effects"**

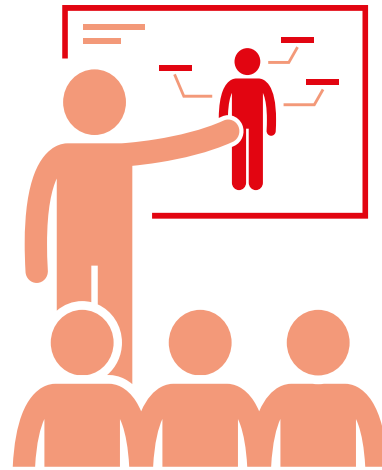
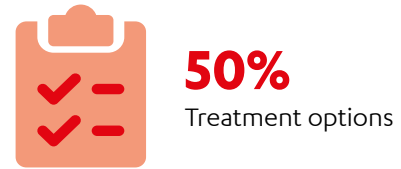


Almost half say that they believe current **treatment options for blood cancer patients are inadequate**

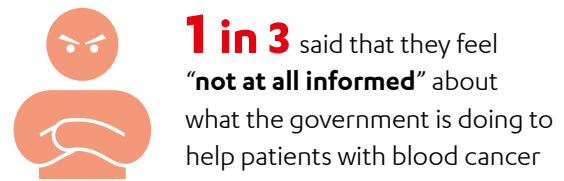


*When compared to other chronic disease (such as HIV/AIDS, diabetes, hepatitis, breast cancer). Janssen. Make Blood Cancer Visible survey (2018).

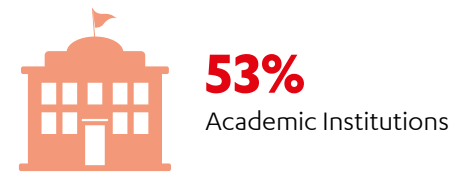
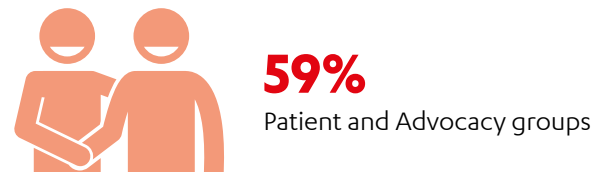
The public wants to know more about blood cancer. Overturning fear starts with more information. They would like to know more about the prevention and treatment of the disease.



Knowing what the government is doing to provide better support for patients is also key.



The public would like to hear more about blood cancer from reliable resources.



China

Every cloud has a silver lining

Anonymous, 70

Mantle cell lymphoma (MCL)



Currently in my 70s, I am recovering from a serious medical condition.

Four years ago, I was diagnosed with stage four mantle cell lymphoma (MCL). At that time, my blood examination results were dire: lymphocyte 130 (10 x9/L), blood platelet 30 (10 x9/L), and 87% abnormal lymphocytes in my marrow. I was advised to receive treatment immediately.

I had no knowledge about lymphoma. While I was aware that my lymph nodes under my jaw and groin had been swelling for years, I never took them seriously or thought I needed medical attention.

It was only after speaking to my doctor that I realized the severity of the disease. After getting home, I started researching on lymphoma. I learnt that the average life span for a person with MCL was only three to five years.

Only three to five years?!

I still felt young, and thought I had many years ahead of me. I was full of regret, and truly thought, "This is the end".

Looking back on my life thus far however, I recounted the many tough times I had overcome through my own determination. I knew that I had to keep fighting for my life. What would life mean to me if I were so frightened by this disease that I died without opting for treatment?

"Life is a journey; it's about the process and experience rather than the destination. Life is given meaning from the energy we put in, and not the goals we reach."

At that time, a double blind clinical trial was underway in hospitals throughout China and was recruiting suitable

patients. Luckily, I was chosen to take part in the clinical trial.

The beginning was very tough: I often had fevers and shivers, and the chemotherapy gave me allergies and rashes. I felt sick, had no appetite, and suffered constipation, a lung infection and an activation of Hepatitis B.

Despite the initial struggle, I made it! My lymph nodes shrank, and the tumor was under control and gradually alleviated. More than a year into treatment, I finally achieved complete remission (CR)!

However, my wardmate wasn't so lucky. Intensive chemotherapy caused severe marrow suppression in his body and he died from a lung infection. He was frightened by the disease and constantly worried about the chemotherapy treatment. He eventually succumbed to the disease.

It was an unusual year. I was very fortunate to find House086.com, a lymphoma patient group in China, and joined the organization's MCL QQ and WeChat groups. I eagerly looked up information and learned more about lymphoma. After studying now for a number of years, I have a much better understanding about MCL.

I must thank House086.com for building a platform that allows patients to communicate with each other. In the group, we exchange information and share our treatment experiences. Now, I use what I have learned to answer new patients' questions, take part in organized activities, and call upon the government to add MCL target drugs into the medical insurance essential drugs list.

After the alleviation of my disease, I've had a new lease of life. I started walking, doing Tai Chi and swimming. Whenever I could, I'd go on trips to explore and enjoy my life.

I have learnt so much from facing this disease.

My hope is that other patients can similarly stand up to this condition courageously, and can overcome it!

There is an ancient saying: "a disease often helps to extend life".

May those of us in remission place a greater importance on staying healthy, and live a happier and longer life!

India

Blood Cancer Insights

The facts

India has the **third** highest number of blood cancer patients in the world after the US and China.¹⁸

Blood cancer contributes to **7%** of all cancer cases in India.¹⁹

Data may be underestimated. The real incidence of all cancers is expected to be at least

1.5 to 2 times higher,

as suggested by data from large screening studies and low coverage of Indian cancer registries.²⁰

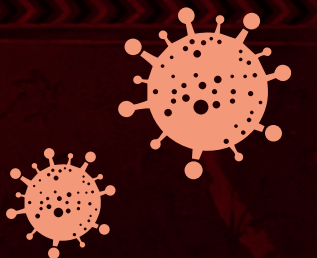


80% of cancers in India are detected late.²¹

Only 20-30% of cancers are diagnosed in Stages 1 and 2, which is less than half of that in the US, UK and China.²⁰

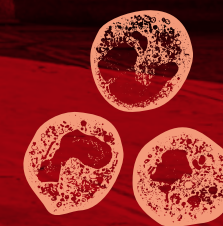


Late detection is the cause of **70% of cancer deaths in India.**²²



India continues to remain the largest contributor to cancer deaths at

2.2 million every year, of the global figure of 8.8 million.²²



The ratio of oncologists to newly diagnosed cancer patients is

about **1:677.**²³



Gujarat, India

Never give up

Karan Vyas, 25

Chronic myeloid leukemia (CML)



I am Karan, and I am 25 years old. I was 10 when I was diagnosed with chronic myeloid leukemia (CML) in 2003. At that age, I didn't know what CML was or what having the condition meant. All I remembered was watching my parents and family members crying, and feeling shocked by their reaction.

I didn't understand why my mother was crying so much. She didn't respond when I asked her why she was crying, but I assumed that something must have been very wrong about my health.

We consulted many doctors, and I saw my family getting increasingly upset.

At the time of diagnosis, I was hospitalized and underwent treatment, so I was often absent from school, which greatly disturbed my teachers.

We then met a specialist at Ahmedabad, who told us that there is a new treatment which can successfully combat CML. With the help of The Max Foundation, I was able to begin treatment. My blood count came under control, and my loved ones were relieved that my condition could be overcome.

It was only after I got older that I came to know these details.

In 2006, my parents finally told me that the medication I've been taking was to treat CML and they explained everything else about the condition. I was sad, worried and stressed to learn that I had blood cancer. For two to three years, I had been taking medication and didn't know what for. My mother told me that they kept it from me as they were worried that I might get depressed.

Before I knew about my cancer, I was living a care-free life, not worried about anything.

Despite my condition, I did well in school and completed my Diploma in 2011, which admitted me to the Bachelors of Mechanical Engineering. In 2015, I took up Sports Rifle shooting which took all of my interest. I advanced in the sport, and was placed first in that batch. My coach was amazed and told me "shooting is in your blood, child."

I believe I had a talent for shooting, and God proved it by encouraging me and allowing me taste success in that

sport. I won district-, and state-level championships. I was determined to be the best shooter, and longed to enter the Indian National team, with hopes to compete in the Commonwealth Games and even the Olympics!

It has been three years since I started rifle shooting, and have won a total of 13 GOLD medals thus far. During this period, I also suffered from tuberculosis (TB) in 2017. I experienced pain in my chest, and was coughing for two months. I was participating in the state as well as national championships during that time, and was upset TB came in my way.

I used to take TB medicines in the morning and CML medication at night. It was a hard time for me as I had to train daily for my upcoming championships. I fought TB for six months. At the end of 2017, my TB was finally cured. I had lost so much of weight because of it; I am presently gaining my weight again.

I just won a medal in the national shooting championship held in December 2017. These days, I am training for the India team trials in rifle shooting. I practice daily for six to seven hours, firing 50 to 100 rounds. I run two kilometers every day, and I am fit as never before. I am confident of what I am pursuing and that I will achieve what I want. Rifle shooting is my passion and I will get into the Indian team soon.

Over the past fifteen years, I've fought against CML, TB, one kidney stone surgery and even some emotional breakdowns surrounding personal and family issues. Every time I faced a problem, I fought and never gave up.

"'Never give up' became my motto, and now I know I have the capacity to fight and persevere."



I also know who I am - I am a shooter. I thank God for giving me CML that has given me courage to overcome any problem in my life.

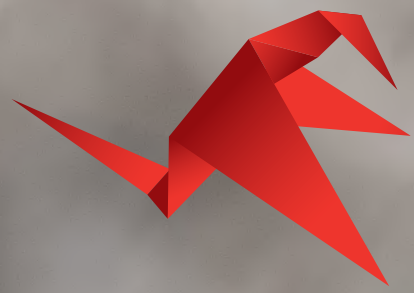


Mumbai, India

When the impossible becomes possible

Suresh Pawar, 46

Chronic myeloid leukemia (CML)



I was leading a good life and enjoying every bit of it. But destiny has its own ways. In July 2005, calamity struck.

I had started falling sick repeatedly. My weight decreased, I often ran a mild temperature and suffered pain in my joints. Due to an enlarged spleen, my appetite too was affected. Doctors advised me to do conduct a full blood count as well as other pathological tests. After a few days, the reports showed that I had tested positive for chronic myeloid leukemia (CML). My white blood cell was in the range of 127,000 and my platelet count was high.

My world came crashing down and my family was most troubled with the news. I was only 34 and it was such a blow. I worried about my wife and kids and their future. The thought that my children would grow up as orphans, like I did, broke me.

I was born in a poor family comprising four siblings and uneducated parents. My father was an alcoholic and my mother provided for us by doing domestic jobs. Life was very tough and each day a struggle. When I was nine years old, my father passed away due to alcohol related problems. We were shattered, but stood up in the face of tribulation.

Fortunately, I was admitted into a government-aided institution for orphans. Education, accommodation as well as meals were provided at no cost. This golden opportunity which came my way was a turning point in my life. I dreamt of becoming an electrical engineer and living a good life. To make this a reality, I worked very hard and put a lot of effort in my studies – and saw success. Having completed my diploma, I secured a prestigious job as a sub engineer.

I was working hard. My dream of having a good job and owning an apartment was fulfilled. Subsequently, I got married to my beautiful wife and had two lovely children. I felt complete and began dreaming of giving my children the best education and a comfortable life.

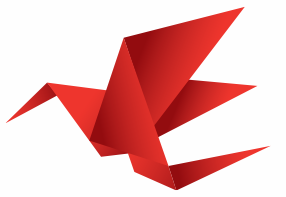
Unfortunately, destiny would not have it my way. My life came crashing down when I was diagnosed with CML. I was shattered once again. I felt like I understood how a person on a death sentence would feel; our days were both numbered.

My hematologist encouraged me to seek treatment and after initial investigations, I was advised to opt for a bone marrow transplant, which had a success rate of only 47%. I knew this option was beyond my reach as it costs about

Rs. 1.7 million – an amount I would not be able to afford even if I sold all my assets.

My future seemed very bleak, and I was dreading the thought that my end was near. Yet,

“I was silently mustering up courage to fight the deadly disease. I always had a fighting streak in me.”



I soon saw a ray of light when my doctor informed me of a new drug, which gave effective results and was available at no cost from The Max Foundation. I will never forget that glorious moment – it was October 2005 when I entered The Max Foundation office for the first time and met one of its staff. She lovingly held my hand and said, “Do not worry my son, you are going to be completely cured.” Hearing those comforting words, I knew there was no looking back.

My treatment commenced soon after and in spite of a few side effects, the first month showed a lot of improvement. My CBC report was normal and I put on little weight. I became very optimistic and enthusiastic about life once again.

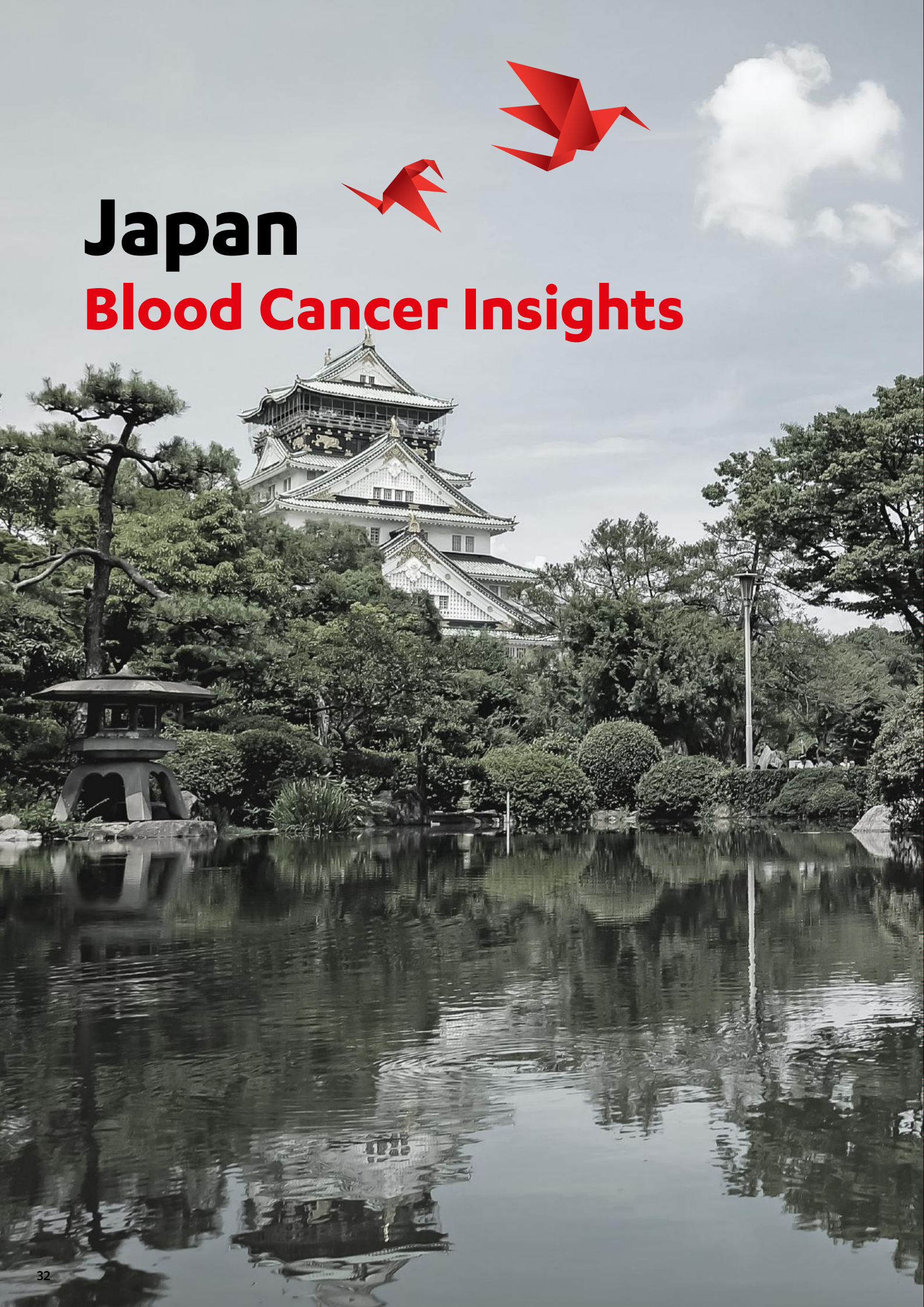
I also started attending various meetings and met many CML patients and survivors. I feel very fortunate when asked to participate in knowledge sharing and motivational programs. As a volunteer, I am glad to be able to contribute and give back.

I have been victorious in my battle against cancer, and there is no stopping me. I now have the chance to live, and want to live a fulfilled life – I continue to do my bit for orphans by conducting programs on ‘safety’, ‘environment’, ‘cancer awareness’ and other motivational topics. I remain an active volunteer.

I am truly living a happy life, and have come to realize what “living a good life” means. I may be living with blood cancer but not suffering from it. My message to newly diagnosed cancer patients is don’t give up, stay positive and think positive. Keep working at your dreams, and extend help – be it emotional or financial – to cancer patients in need.

Japan

Blood Cancer Insights



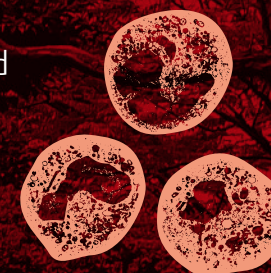
The facts

The three types of blood cancer tracked by the National Cancer Centre (malignant lymphoma, multiple myeloma, and leukemia) make up about 5% of all cancers in Japan.²⁴

Multiple myeloma is the third most common form of blood cancer in Japan,²⁵ with

8,200 cases projected in 2017, and more than

4,000 deaths in the same year.²⁶

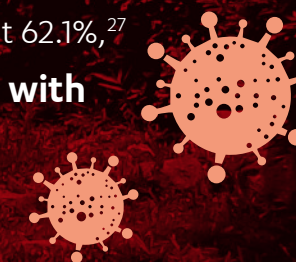


In 2013, there were

11,968 cases of leukemia in Japan.²⁴



Although Japan's five-year cancer survival rate is at 62.1%,²⁷ the **five-year survival rate for patients with blood cancers** like leukemia in adults (33.3%) is **lower than** the United States (46.7%) and Australia (51.8%).²⁸



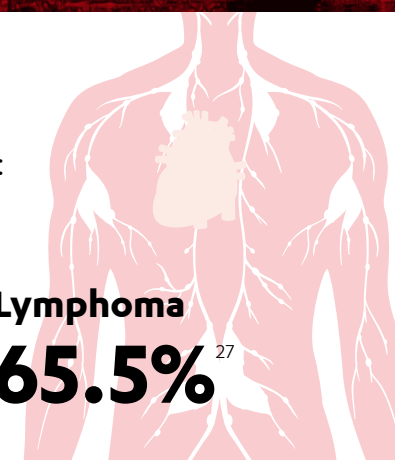
Other five-year survival rates for patients in Japan:

Lymphoma
65.5%²⁷

Multiple myeloma (MM)
36.4%²⁷

The mortality rate of MM in Japan was

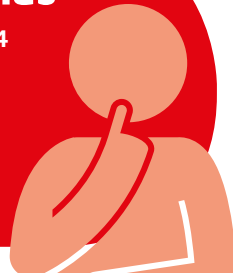
3.5% in 2016.²⁹



In 2017, Janssen Asia Pacific undertook a study in Japan asking 1,000 members of the general population about blood cancer. The study revealed the need for more work in making blood cancer visible. The results are featured in the pages that follow.

Japan Study Insights

Blood cancer incidence has been growing in Japan,²⁴ yet overall awareness is still low.



Only 1% of the public says that they recall seeing or hearing anything about blood cancer in the last year.

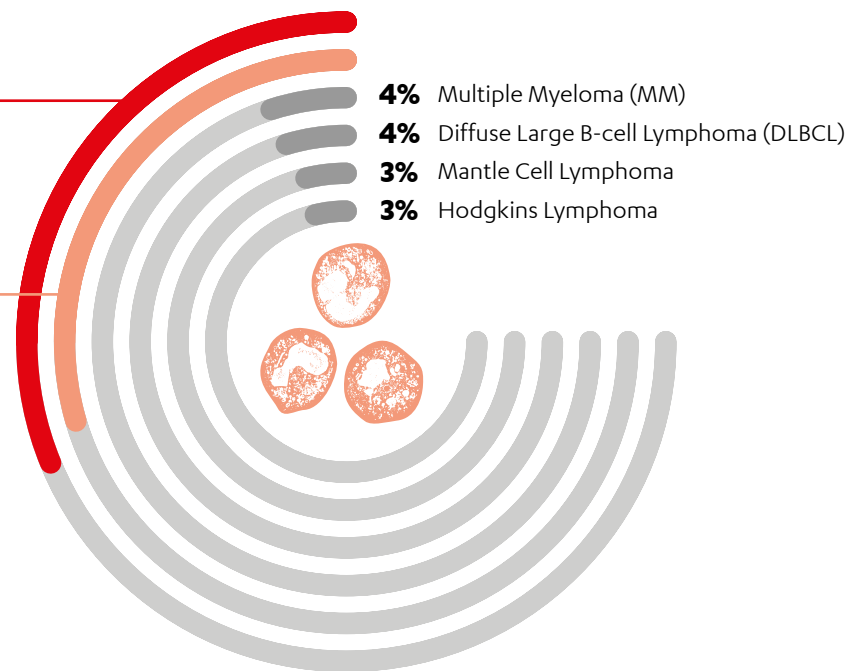
1 in 2 could not name a single symptom of blood cancer.

A big misconception is that blood cancer is only one type of disease.

Most in Japan could only name leukemia.

25% of respondents could only name **Acute Myeloid Leukemia (AML)** as a type of blood cancer, while

24% only know **Chronic Lymphocytic Leukemia (CLL)** as a type of blood cancer



Decline in awareness is more pronounced in the younger generations, which is a potential stumbling block to early detection or prevention efforts.

67% of people who admitted that they “don’t know anything” about blood cancer were under the age of 34



Low awareness contributes to a very grim outlook on blood cancer, as well as a number of misconceptions.



Low Survival Rates

89% of respondents **don’t think or don’t know** if a patient diagnosed with blood cancer has a good chance of survival



Poor Quality of Life

Even if a blood cancer patient survives, **77%** are **unsure** if they can achieve quality of life with proper medications.

More than half said that they are unsure how fast the disease will progress



When compared to other chronic diseases (HIV/AIDS, hepatitis, breast cancer, diabetes), patients with blood cancer were thought of as least able to **manage family commitment (like housework, childcare, etc)** and **work long hours or overtime if needed**

Limited understanding of treatment options may lead to fears and misconceptions.



More than half are unsure if blood cancer will require surgery for treatment



97% question whether or not current treatment options for blood cancer patients are adequate



Myths



1 in 2 respondents were unsure if blood cancer is **contagious**



Only **9%** know that blood cancer is **hereditary**



Others attribute blood cancer to **poor lifestyle choices** like drinking or smoking

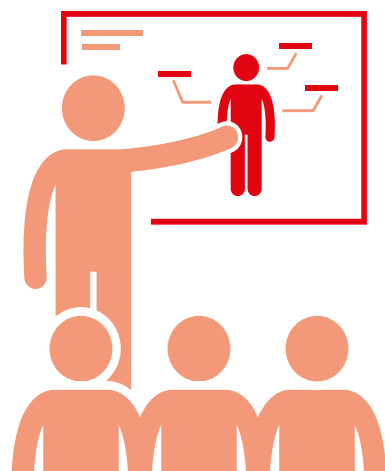
The public is eager to know more. 1 in 3 said they could use more information about blood cancer. The top two topics of interest are:



Treatment options



Patient experiences



Working together will help empower patients and their caregivers. It will take information from multiple sources:

Respondents said that they would like to hear from not just one but a variety of sources.



54%

Government / health boards



43%

Media



38%

Private companies

Addressing the fears and misconceptions around blood cancer through a multi-platform dialogue is key to building the foundation for better support for blood cancer patients in Japan.





Tokyo, Japan

Overcoming fear

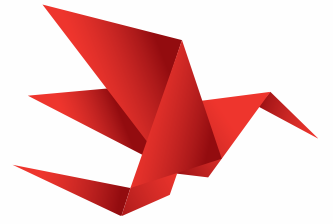
Anonymous, 45
Multiple myeloma

I was teaching music in a Japanese school overseas when I was advised by a local clinic to seek treatment in Japan because there was a possibility that I had multiple myeloma. This was in 2009, and I remember that day clearly as it was exactly a year after I got married in August 2008. At that time, I somehow felt a sense of guilt for making my wife the spouse of a cancer patient in less than one year of marriage.

As I started collecting all kinds of information about the disease, I learned that the average survival period is about five years. I became extremely worried about what I would be leaving behind in five years, and what I could do especially when I had just started to build a family.

I returned to Japan, and in 2010, underwent two transplants. I remained in a good state thereafter without requiring any treatment for more than a year. Initially, I went to the hospital every month, but as the gap between visits stretched longer to six months, I was very happy that I didn't have to go to the hospital for longer periods of time. I further felt a mix of worry and relief; on one hand, I was concerned that the disease would return, but on the other, my condition was stable for more than a year, which gave me a sense of comfort. Fear and confusion often gripped my heart each time I thought about the what-ifs. For example, what if I relapsed and there are no effective drugs that can treat my condition?

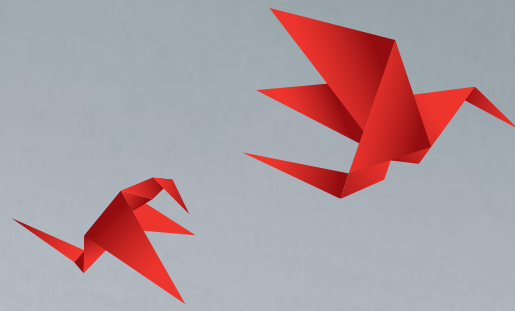
“These days, there are many treatment options, so I am confident that I will extend my survival period with the right treatment.”



Now I focus on spending time with my family and being active outside home. One of the activities I love is singing, and I try to do this as often as possible! I hope that other patients will also succeed in their treatment as I have, so they can do the things that are truly important in their lives.

South Korea

Blood Cancer Insights



The facts

Leukemia and non-Hodgkin lymphoma are the **top two** most common forms of cancer in both sexes for the 0-14 age group, and within top three for males in the 15-34 age group.³⁰



The number of newly-diagnosed chronic lymphocytic leukemia (CLL) patients every year in Korea is approximately

60 individuals.³¹

Multiple myeloma is a blood cancer that affects about

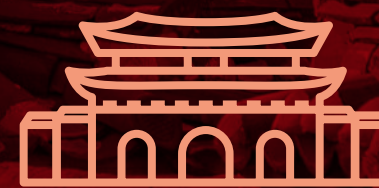
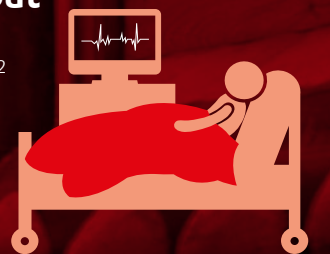
6,500 people in Korea with more than

80% of patients over the age of 50.³²

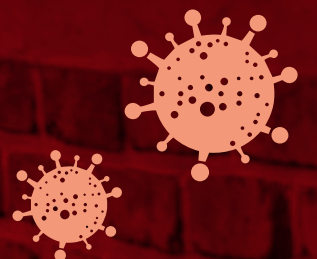


Most patients experience a relapse or resistance to existing treatments with the average **survival rate for these patients being about**

5.1 months.³²



The incidence of multiple myeloma (MM) in South Korea has **doubled over a 10-year period**, and based on recent national cancer registry data **increase was 10 times** compared with MM incidence of 20 years ago.³³

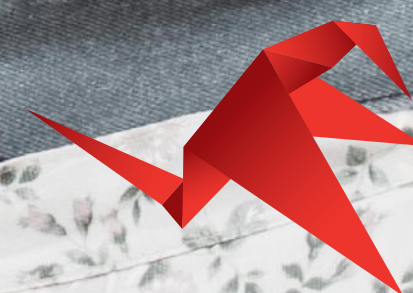




Seoul, South Korea

What is your survival rate?

Yu-Jin Hong, 30+
Chronic myeloid leukemia (CML)



100 - 85 - 10 - 70 - 50 - 70 - ? %

These numbers are the survival rates I have heard. Would you listen to my changing story?

In 2013, the left side of my stomach began to protrude and become stiff with a sharp, stabbing sensation, so I visited my neighborhood doctor. Over the course of two years, I had lost more than 10kg. I was always tired and bruised easily. These symptoms had been progressing slowly but because I had been so busy at work, I hadn't had the time to consider them seriously.

So, when the doctor suspected cancer, I thought that there was no way that this could be true.

However, my blood test came back with abnormalities, indicating chronic myeloid leukemia (CML). My doctor said, "If you take medicine and maintain your condition well for the rest of your life, you won't die. Your chances for survival are 100%, so don't worry."

To be honest, his words did not reassure me. The image of a blood cancer patient I had in my head was an actress, with deathlike pallor, blood spilling from her nose as she died.

I had never met anyone with blood cancer living a healthy, productive life.

Full of anxiety, I began to search the internet.

"Innovations in targeted therapy make it possible for patients with leukemia to live like those with high blood pressure!"

"Long-term survival rates exceeding five years have increased to 85%!"

Most of the articles I found supported the doctor's rosy prognosis. Even so, they also revealed that just 10 years prior blood cancer was a frightful disease in which most patients died within a few years of diagnosis with low transplant success rates.

There was no way of knowing whether I would be a part of the 85% that would survive beyond five years or the 15% that wouldn't make it.

Moreover, even at 85%, I could not even imagine a life that could not be continued beyond five years, and a life

that could not be planned for the future.

I was in my 30s, and when I looked into the future—it was bleak. The life that I had known up to this point looked back at me with the mask of death.

When I visited the general hospital just a day after consulting my neighborhood specialist, my condition had worsened.

They immediately admitted me to the intensive care ward; my bone marrow test results determined that I was in blast crisis — acute stage of leukemia.

I was told that if I didn't receive a bone marrow transplant within six months, my chances for survival were low; in fact, doctors were even questioning whether I could go for the transplant.

A doctor informed me that my survival rate at that time was about 10%.

Soon, chemotherapy began.

For six months beginning October 2013, I received targeted therapies combined with three rounds of aggressive chemotherapy which required me to be hospitalized for four to six weeks at a time. The treatment involved killing the cancer cells by also killing all of my own immune cells at once, rendering me with zero immunity.

The only thing I could do during this time was give it my best.

I gave up work, and followed the instructions of the medical staff and ate the hospital food so that the anticancer drug had a good effect. I developed enteritis, which caused diarrhea and pneumonia, which caused me to cough so hard it felt like my throat was ripping. Yet, I kept eating.

To ensure that the anti-cancer medications didn't destroy my kidneys, I kept up with drinking the corn tea that my mother made for me.

To calm my turbulent mind, I read Albert Camus' "The Plague," Jose de Sousa Saramago's "Blindness," Shakespeare's "Pericles" and imagined the plights that these fictional characters endured as they soldiered on in their lives.

It helped me get out of the swamp of self-pity.

The suffering I was experiencing was not a trial that others had not faced, and perhaps it was not such a severe destiny, I thought. It too would someday pass.

Trust in my medical staff, support of family and those close to me, and efforts not to fall into self-pity have become a great force for me now in the post-transplantation phase, and during the course of the difficult chemotherapy.

My cancer cell ratio had fallen to 0% after the first-line chemotherapy.

My only brother also turned out to be a donor match, which settled that worry.

My doctor looked at me with a bright face and said that my transplant success rate was about 70%. Yet within a few hours, the results of my bone marrow test revealed that the success rate was actually closer to 50%.

Luckily, my condition improved and I decided to go through with the transplant.

Four years have passed since May 2014, and I am still living healthily to this day!

In three years, I've had nine follow up genetic tests and each time my results indicated 0% (negative) cancerous genes.


From last year, I started to walk back to my way of life. Leukemia awakened the writer in me. Next year will be the fifth year since transplantation; holding that as my milestone, I am working towards finishing my autobiography, and wonder what will my survival rate be then?

Perhaps some reading this story will think that this hopeful change in survival rate is a special luck given to me and that I am an extraordinary case. But it is not. In fact, in leukemia patient group meetings, I've met many survivors who once had survival rates as low as mine but also made it through.

Thankfully, many of these stories are in the handbook written by Korean CML-survivors, "Sorry for Always Being Sick" as well as in this "Make Blood Cancer Visible" report. So this is also a story that you and those close to you and medical staff will make together.

What is your survival rate?

Do not forget it! Your number may be bad now but it will not stay there forever; it is changing even at this very moment!



“The suffering I was experiencing was not a trial that others had not faced, and perhaps it was not such a severe destiny, I thought. It too would someday pass.”



Seoul, South Korea

A change in priorities

Anonymous, 37

Diffuse large B-cell lymphoma (DLBCL)

I am a 37-year-old man living in Korea. I was diagnosed with lymphoma and underwent chemotherapy and radiotherapy. Thankfully, I don't need further treatment because I haven't had specific symptoms for the last seven years. I hope my story is of help to patients who are newly-diagnosed or currently being treated for blood cancer.

In 2009, my annual employee health screening revealed a strange mass in my lung and I was advised to go to a general hospital for detailed examination. It wasn't confirmed that I had lymphoma then as I was deemed to be too young to have cancer. A lung tumor was suspected, so I was sent to the Department of Thoracic Surgery. A thoracic surgeon referred me to the Department of Hemato-oncology again, saying that mediastinal malignant lymphoma has been increasing among young people. That's how my struggle against the illness began.

I did not have special symptoms. I didn't have night sweats and my lymphatic nodes were not large enough to be noticed. I had a cold whenever there were weather changes, but it was not serious. I often felt tired, but I thought it was chronic fatigue caused by overwork.

I was informed of my biopsy results about a month after the abnormal mass was detected. At that point, I couldn't imagine that it would be cancer and thought everything would be okay once the tumor was removed. I was in the doctor's room with my parents when the doctor told me that I had a malignant lymphoma. Unsure what that meant, I asked if it was cancer. He said it was a hematologic malignancy. My parents turned pale and my mother almost fainted.

Once we got home, I immediately applied for a medical leave of absence and started preparing for chemotherapy. My friends and relatives were shocked to hear about my illness, yet my parents were the most heartbroken. I feel so upset whenever I think of how much it must have hurt them.

After nine months of treatment, I was back to my normal life. Treatment results were very good without serious adverse effects. However, I was constantly afraid that the cancer would return. I began to suspect that even a fever caused by a cold was symptomatic of cancer and couldn't concentrate on my work, so I left my job one month

later. My employer kindly redeployed me to another part of the company to make my work easier and my coworkers were considerate towards me. Nevertheless, I was always anxious about my health, thinking: what if I get sick again because I work too hard? What's the use of earning money if I die?

As I said, the biggest change after battling cancer is switching my life priorities. When I was healthy, my priorities were to have a good job, make money, win competitions, and be successful. However, what is important to me now is life satisfaction, happiness, and today's joy rather than worrying about an uncertain future.

For almost a year, I did not work and exercised hard to regain my health. Fortunately, I got to know the Korea Blood Cancer Association, which helps patients with blood cancer such as lymphoma, leukemia, and multiple myeloma. Initially, I was only a volunteer but am now a full-time employee of this organization. Besides, I met a great woman who understood my medical history and we are now a happy family with a four-year-old child.

There is a phrase that I pondered on during my struggle with lymphoma: 'Everything has its pros and cons'. Had I not fallen sick, I would have worked harder and earned more money, but would not have realized the importance of family. It is extremely rewarding for me to help patients lead a happy life by balancing work and family.

“Cure rates are merely statistical figures. Cancer is no longer an intractable disease since new drugs continue to be developed, allowing the condition to be managed, just like hypertension or diabetes.”



Of course it is best not to have cancer, but if you already have it, it is better to accept it, learn about the disease and receive treatment. I would like to encourage all patients and their families who are reading this that believing that you can overcome the condition will lead you to good results. I pray for your complete recovery.

South and Southeast Asia

Blood Cancer Insights



The facts

The availability of blood cancer statistics across South and Southeast Asia varies from nation to nation. For example, there is no population-based cancer registry in Bangladesh, nor a national cancer registry of any kind.³⁴

WHO predicts that the number of blood-related cancer cases in Southeast Asia will increase by about 50% by 2030 as compared to 2012.³⁵

Leukemia

In Southeast Asia, countries with the highest estimated incidence rates:³⁶

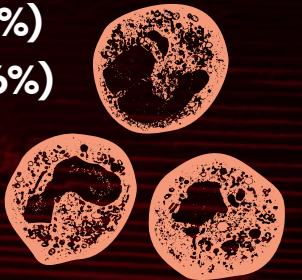


1. Singapore (6.8%)
2. Malaysia (6.2%)
3. Indonesia (5.9%)



1. Vietnam (6%)
2. Malaysia (4.8%)
3. Myanmar (4.6%)

Leukemia contributes to 4% of all cancer cases in Thailand.³⁷



Lymphoma

In Southeast Asia, countries with the highest estimated incidence rates:³⁶

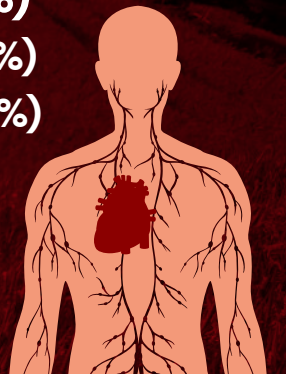


1. Indonesia (2.4%)
2. Singapore (2.3%)
3. Thailand (1.8%)



1. Brunei (4.1%)
2. Indonesia (1.9%)
3. Singapore (1.7%)

The **five year incidence for lymphoma** in Malaysia between 2007 to 2011 is **5,374 patients.**³⁸



Myeloma

There are about **100 new cases** of **multiple myeloma** in Singapore each year.³⁹

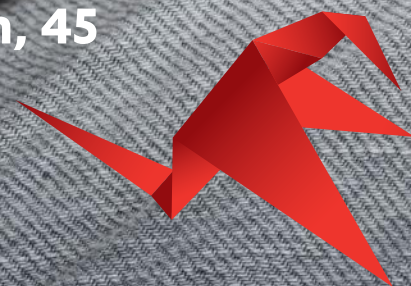




Dhaka, Bangladesh

An unimaginable outcome

Ebna Habib Md. Shofur Rahaman, 45
Chronic myeloid leukemia (CML)



When I was a student, everything was smooth-sailing for me. I had brilliant results, and graduated with Masters in Horticulture from Bangladesh Agricultural University. My supervisor was very pleased and offered me a fellowship for pursuing a PhD degree, where I enrolled in June 2002. Physically, I was very strong and sporty, but was losing weight gradually day by day. I attributed this weight loss to the amount of effort I put into my work. However, it continued for months and I was getting lean and thin.

In July 2002, one of my friends brought me to visit a physician in Mymensingh, and he suggested that I do a few medical tests. The physician keenly observed the report and wrote a comment in the prescription **“Diagnosis: CML.”** I didn’t know what CML was, but he told me it was a blood related problem and not to worry because treatment was available.

I searched the Internet to learn more about CML, which stands for chronic myeloid leukemia. It was then that I realized that the condition is a type of blood cancer. I couldn’t accept this to be true. I went to Dhaka to seek a second opinion. However, I got the same result. The hematologist suggested that I undergo chemotherapy. I was devastated.

All alone, I thought about what I should do. I didn’t inform my parents about my illness as I was fearful that they would get heart failure after finding out. I felt very helpless and cried a lot. A day or two later, I cautiously informed my parents about my illness, requesting for their patience and to pray for me. The news eventually spread to everyone, and many came to visit me as they thought I would leave the world very soon. This was unbearable!

I knew I had to fight on and within couple of days I gained the mental strength to visit a specialist in Mumbai, India for a final diagnosis and better treatment.

I was given a lot of medical tests, which revealed the same results. I finally accepted that I had CML. The doctor advised that I choose one out of three treatment options: Bone marrow transplantation, a fairly new oral treatment, or chemotherapy. My father and I discussed overnight and decided on the oral treatment. It was

recently available in my country, but the cost was very high.

I started the treatment and funded it on my own up to December 2002. While I made miraculous improvements in my health, it was terrible in every other sense, economically and emotionally, as I had to spend my parents’ entire savings to buy medicine for the last five months of treatment. My brother and sister were still students at the time.

To be honest, it was a really difficult period for me. As non-government service holders, we didn’t have any insurance coverage. We had nothing. I was praying a lot, asking God to give me strength to face what I had to live through. I spent a lot of time searching for private donors or charity organizations that could help CML patients. I came to know about a support program by The Max Foundation and applied for assistance. Ten to 15 days later, in January 2003, they called and told me that I was eligible for the patient support program and asked for me to send some compulsory documents immediately.

Ever since, I’ve been supported by the program and I am keeping well. I’ve completed my PhD degree, found a job, got married and am blessed with a daughter of eight years and a boy of five months – an unimaginable outcome given my situation in 2002!

“My illness gave me more than enough strength to keep going. I have a strong desire to work and the spirit to drive ahead.”



I’ve established a patient support group in Bangladesh in 2013 to provide mental support to affected families, create awareness, reduce stigma on cancer and developed a network for support and care. When someone is affected by blood cancer, the group takes the responsibility to guide them in the right way to ensure the best treatment.

I’ve put aside my sickness, and I now want to live long and continue contributing to society!



Dhaka, Bangladesh

Finding hope in darkness

Moshaddek Alam, 32

Non-Hodgkin lymphoma (NHL)



I was diagnosed with non-Hodgkin lymphoma (NHL) when I was 27. It became a source of both fear and strength for me.

At first, it caused fear. I had just started developing my professional career as a facilitator. I never thought I would deal with the Big C (cancer) in my life. I distinctly recall the sleepless nights and struggles in deciding how to share it with my family and friends. I could not think of anyone who had it. No one in my family had the condition either.

Sometimes I would think everyone was moving forward while I was stuck. This sentence perfectly described my situation before I underwent my chemotherapy treatment, which lasted just 147 days. My pillows would often be soaked with tears. I kept uttering two words to myself – Why me?

Looking back, I've come to realize how dangerous that period of darkness was – I could have easily been defeated by my illness.

On the other hand, despite pain, despair and fear, my battle with this illness has given me so much hope and strength. My victory over cancer has given me a renewed confidence to run on any track and win.

The tumor on my neck completely disappeared in the first round of chemotherapy, which signaled a hopeful beginning. My line manager would always tell me, "Never think about why. Instead, always think about the how when you are in an unwanted situation." This greatly fueled my desire to survive.

As I sat in my balcony, and watched night give way to day and darkness turning into light, I was motivated to improve my situation.

I am now living in the light and have joined survivor groups on social media. Positive comments of other survivors have supported me. They have taught me that the Big C has both strengths and weaknesses – if you think about your weakness, the Big C wins, but if you keep your strength, you defeat it.

My experience as a cancer patient changed me inside and out. I find social support is highly important for hope and strength. Supporting the affected does not cost a fortune, it just requires interest and good will. A person who has gained motivation through those who support him will easily defeat the Big C whatever the situation.

An advocate is the motivator who believes the mind is stronger than the body. Big C can be defeated against impossible odds if the sufferer meets an advocate in the virtual or real world.



“The more one learns about the disease he or she suffers from, the better his or her capability to manage the disease.”

There are many diseases that cause sudden and immediate death, but Big C is different from them since it does allow time if one tries treatment. This is why Big C is so special to me. When guests visit our house, we serve them food; in the same way, when Big C touches us, we should serve her treatment as food.

I am grateful that this chapter has passed, and I am living the second year of my survival. It is normal for the affected to remain clueless before treatment, but seeing treatment as light and love makes it easier to go through the journey. I confess that the Big C is life changing, but anyone with strong confidence, support and patience can defeat it and live a normal life.

What I desperately needed in my dark period was proper guidance. It is really difficult to get mental support while you are between death and life. Those that are touched by the Big C passionately await friendliness and hope from doctors, but they often find these professionals reserved.

Therefore, advocacy can strengthen the affected who live in fear by bringing hope. It contributes to destroying the “foreign invaders” in the body.

As an NHL survivor, I am a natural advocate. People pay attention and get curious about my story since I defeated my disease. Sometimes, people hardly believe that I am a survivor because they find no difference between a healthy person and myself. I enjoy talking to the affected, caregivers and physicians. I call and write letters on social media, meet those who desperately need help and support them in the best way I can. If we all work for the affected, we will be able to offer them hope and help defeat the Big C.



Selangor, Malaysia

A second chance and a new beginning

Anonymous, 57
Chronic myeloid leukemia (CML)

I am a full-time homemaker happily married to my husband and have three daughters. In 2008, at the age of 48, I was diagnosed with a rare type of white blood cell cancer called chronic myeloid leukemia (CML).

It all began when I went for a blood test for the first time in 10 years, on 15 November 2008. The results would dramatically alter our lives forever. The GP informed me of the unusually high white blood and platelet count in my blood, and she suspected that I was suffering from some form of blood disorder.

I was in disbelief as I had not experienced any sickness or symptoms up to the time of the blood test. I called my husband, who would later become my caregiver, and informed him of the bad news. His immediate response was that there must be an error and requested for it to be repeated. The repeated blood test confirmed the result and we were recommended to consult a hematologist as soon as possible.

That night, I cried and could not sleep. Many thoughts popped up in my mind, "Am I going to die? I do not want to die so early! I still have so many things to do! Why me?"

The hematologist shared that before the advance of targeted therapy CML patients would have a maximum life span of around five years. To confirm that I had CML, a bone marrow biopsy was performed the same day and sent to Australia for testing.

I had sleepless nights, became more depressed, could not eat properly and lost 10kg in three weeks. My husband tried to console and support me during this trying time but to no avail. Three weeks later, the results confirmed that I had CML. Withdrawn into a world of my own, I left my husband to discuss my treatment options with my specialist, who said my condition was treatable with the latest targeted therapy drug, but at a very high cost.

We were shocked to find out the treatment would cost around USD 2,500 per month and had to be administered my whole life. My husband was two years away from retirement and we lacked the financial means to sustain this lifelong treatment, while supporting my children who had yet to complete their education.

We were desperate for help and told the hematologist of our situation. He suggested approaching the Max Family Society Malaysia (MF), a local advocacy group set up by dedicated CML patients and caregivers, healthcare professionals and

local representatives of The Max Foundation. The society was set up to provide emotional support and education on the disease for new CML patients and their caregivers.

Soon after, we were invited to attend a workshop for CML patients and their caregivers, where we heard about the journeys of other CML patients.

"Meeting with other CML patients brought us hope and relief as we no longer felt alone."



Six months later, I was accepted into the patient assistance program provided by the Ministry of Health in Malaysia, held in cooperation with The Max Foundation.

With each patient workshop I attended, my physical and emotional condition improved. In two years, I was able to achieve the major molecular response (MMR) that would enable me to lead a normal life.

This was a vast improvement from the pre-targeted drug therapy options that would only allow me to live for five years with a poor quality of life.

After my husband's retirement from his full-time work in May 2010, we decided to take a more active role in the MF by joining as committee members. In 2011, my husband was elected to become Vice President of the society. This led to our involvement in organizing and participating in patient advocacy activities with the various major public blood specialist hospitals in Malaysia. We also attended regional and international patient advocacy forums on behalf of MF to learn, compare and discuss the standard of advocacy work done in these countries. Since joining MF, we have been blessed to participate in the expansion of advocacy activities to include other blood cancer patients.

It has been an incredible and surreal journey for my husband and me since that fateful day on 15 November 2008. From initially feeling hopeless and depressed, we were able to meet many benefactors that helped us overcome our challenges, experienced the joy of returning to our normal lives, and helped new blood cancer patients. Never in our wildest dreams would we have imagined travelling down this challenging and interesting path! I truly feel that I have been given a second chance and new beginning in life!



Bangkok, Thailand

Encouragement goes a long way

Akkalerk Krairiksh, 41
Multiple myeloma



I was diagnosed with multiple myeloma around five years ago. Symptoms only started to appear one to two years before that. I played football regularly, but began to notice my energy levels falling continuously. Before, I could play two back-to-back matches, then it became one match, then half a match, until I could only play for 15 minutes.

I thought I was just getting old, and that it was the result of smoking and drinking a lot. So I decided to play football more often, increasing from two days to four days a week. It didn't get better.

In one football match, I was injured – someone hit me in my ribs.

Normally, this wouldn't hurt so much. This time however there was a tremendous pain when I was breathing, so I went to see a doctor. The doctor's diagnosis was that it was just normal muscle inflammation and prescribed a muscle relaxant. I stopped playing football for about two to three months. When I returned to playing, everything was still the same.

It suddenly became easy to catch a cold, even though I was never like that before. I constantly had a headache, flu, and high fever. I felt immense pain in my chest and developed 30 aphthous ulcers, which caused my whole mouth to become white. I thought it was just low immunity, but I slowly realized that my health was not normal.

I hadn't had my health checked since I was 25. I never seriously took care of my health. At first, I thought there was something wrong with my lungs, so I visited the lung doctor. I had an x-ray and he noticed it looked weird. Then he asked me to have another x-ray in a different posture, which revealed a mass within my ribs. He told me to undergo a lung biopsy that required surgery.

The doctors had to cut two of my ribs because there was a lot of damage. My doctor was initially confused because I showed no symptoms of normal cancer, and multiple myeloma is usually found in people aged 50 to 60 years old. After the lab test however, I was diagnosed with multiple myeloma.

I was 35 years old.

I had to make adjustments to my life. 10 years ago, I was a drinker and smoker, didn't get much rest and frequented bars throughout Bangkok. Now, I take coffee instead of alcohol, and ensure I get sufficient sleep.

I think there is a change in the way I view my life. In the past, I would focus only on my goals and desired outcomes, but I was never interested in the journey that would get me there. This disease has slowed me down, bringing me to an awareness of each step I take – what will happen before I reach my destination?

While I have adjusted my goals, I haven't changed them. Whatever dreams I have, I will still pursue and try to achieve them.

The people I spend time with have also changed. Prior to my diagnosis, I worked very hard to establish good business contacts. However, I now mostly meet with other patients, forming strong relationships with those who have the same disease.

I've received so much from my patient journey.

I like talking with strangers. Waiting to see the doctor at my hospital takes a long time, so I start conversations with the leukemia patients there, who are mostly the elderly. I share what I have learnt about the condition with them. It lifts my worries. Experiences shared help us understand each other from the patient's point of view.

Now that I recovered from my sickness, I am very pleased to help or advise anyone and help them feel better.

You can also be a role model for cancer patients. Don't give up — live your life, even though you have this illness. Encouragement is key to supporting patients, and that is why I always tell my friends,

“You do not have to understand me. Just listening is enough.”



About the study

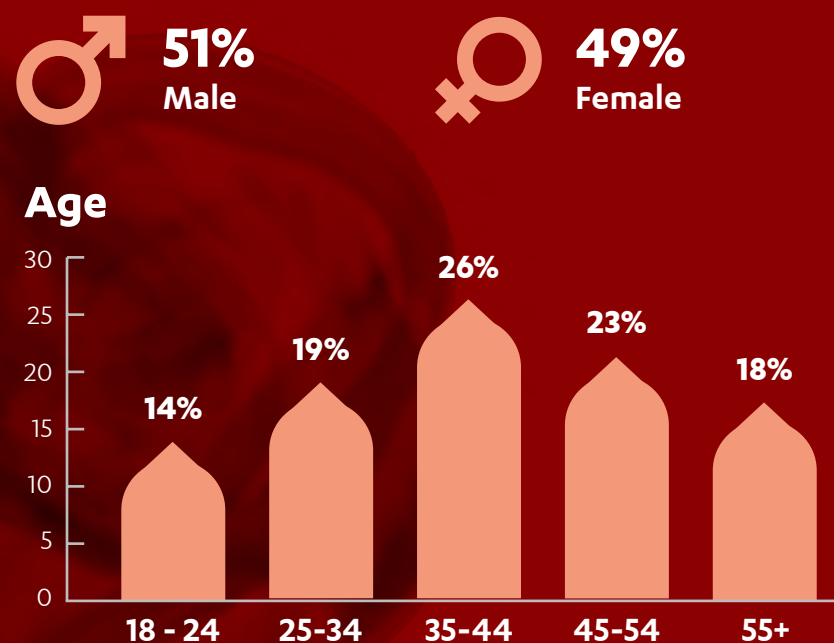
The Make Blood Cancer Visible Asia Pacific study asked 1,000 representatives of the general population in Japan and 2,000 representatives of the general population in China 15 questions about their general awareness and perceptions of blood cancer.

All questions had fixed answer categories and were online, self-administered surveys. To ensure anonymity, all respondents were assigned an anonymous alphanumeric identification to protect their identity.

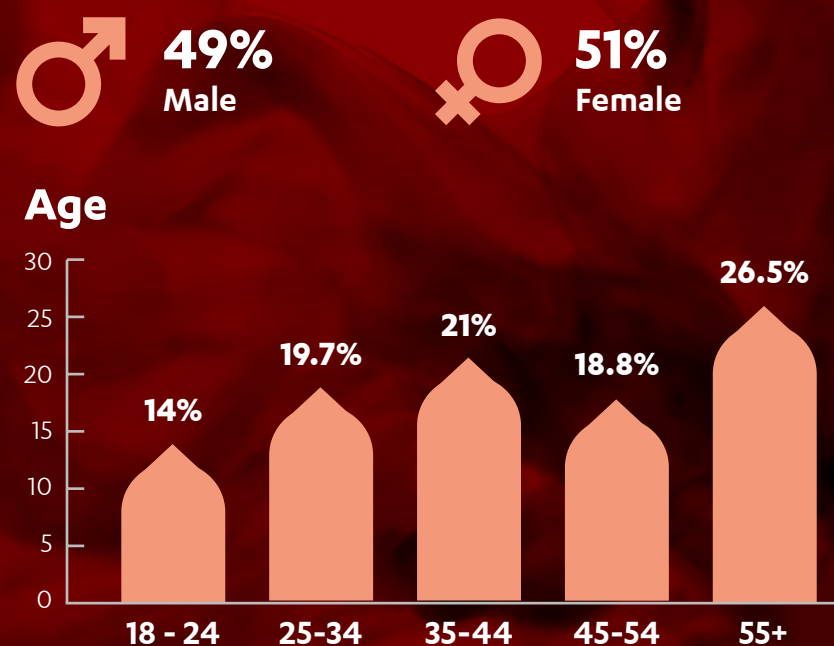
The study was conducted from 1 February 2018 to 8 February 2018 in both countries. The questionnaire was commissioned by Janssen and prepared by Nielsen and YouGov.

Questions focused specifically on public understanding of blood cancer symptoms, causes, available treatments and perception of impact to daily life.

Japan population estimation based on latest census documentation available:



China population estimation based on latest census documentation available:



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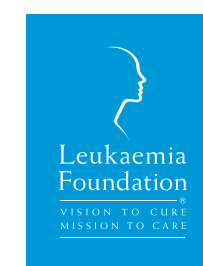
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Australia



www.leukaemia.org.au

Bangladesh



bcmlsg.wixsite.com/bcsg

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friendsofmax.info/home/

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www.maxfamily.org

South Korea



cafe.daum.net/cmlzero

South Korea



www.bloodcancer.or.kr/

Thailand



www.maxsmiles.org



For more information and support, please visit The Max Foundation website at www.themaxfoundation.org

About This Report

The Make Blood Cancer Visible Asia Pacific study in China and Japan as well as the preparation and launch of the Make Blood Cancer Visible Asia Pacific Report were sponsored by Janssen Asia Pacific, a division of Johnson & Johnson Pte Ltd. The stories in this report were written and voluntarily submitted by the patients themselves. The opinions expressed in the stories are those of the patients and do not necessarily reflect the views of the sponsor.

