

Dawn of Hope

15 stories of human endurance,
survival and triumph



Two decades of living with CML
World CML Day 2022

Written and edited by
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The Max Foundation
Accelerating health equity, one patient at a time.



Together we share & learn

Cover Artwork

"Dawn of Hope"

Name of Artist:

Anil P R
(*Ernakulam*)

Diagnosed:

2008

Is there any one amongst us who has not put this down on paper at some point of time in our lives – blue skies, maybe a few birds amongst white fluffy clouds, a river joyously flowing below and a bright yellow sun rising from behind the perfectly shaped mountains - signalling a dawn filled with hope – day after day. One such day dawned some 20 years ago for thousands of CML patients and their families bringing joy and hope into their lives with the gift of life itself, the Magic Bullet. Anil from Kerala who has been on treatment himself for 14 Years created this beautiful artwork which adorns the cover of this book and symbolises these emotions so simply yet so powerfully.

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Editor's Note

This World CML Day it brings me the greatest pleasure to bring to you these 15 stories of human endurance, survival and triumph.

These are ordinary human beings who when faced with an extra ordinary challenge rose up to it and in the process gave a new meaning to their own lives and those of the others they touched . At The Max Foundation we have been privileged to have been part of their lives and their journey and served them with all the care and attention they deserve.

These are men and women , little boys and girls who were told they had cancer and had to live with life long therapy . An accident of life that brought together hundreds , nay thousands, from all walks of life who then found strength and solace in each other - a safe platform upon which to share and learn with and from each other. They called themselves the Friends of Max . Together they found a new normal for themselves and forged a parallel path ahead.

Twenty years is a long time to have traversed together upon a path of self discovery and learning and deserves celebration. This then is just that - a celebration of two decades of perseverance and courage.

This year marks the 20th anniversary of the patient assistance programme that gave thousands of patients the Gift of Life; the advent of what came to be called The Magic Bullet which burst upon the firmament of CML therapy like the brightest star ever.

This year marks the coming together of partners from the world of pharma , non profits and medicine in a project without any kind of precedence.

But most of all this year marks that Dawn of Hope which brightened the lives of so many families in an unimaginable fashion.

Personally for me it has been two decades of discovering every day the power of unconditional love and acceptance.

Working on the outpourings of these 15 individuals and bringing them to you in this fashion has been an overwhelming but oh such a rewarding task . Memories of my first encounter with them have come crowding down upon my consciousness while every milestone they speak about is imprinted upon my mind like it happened yesterday .

Many and varied are the emotions their stories evoke in us yet each one has its own special one that stands out .

In a tribute to both these 15 Friends of Max who have shared their stories and the others who do not feature here , the Max South Asia Team has chosen 15 special art work created over these years during our art workshops that find a reflection of these very emotions on the canvas they used to express themselves .

Finally, thank you dear friends for sending us your precious history and for letting me share them with my own insights . It is like I have come to know each one of you all over again.

You have indeed created history and your words of courage and perseverance are going to make the Dawn of Hope a reality for so many more who embark upon a similar journey each day . You have made the world of CML a richer more humane one with your generosity of spirit.

This book is a celebration of your spirit.

**- Viji Venkatesh,
Region Head, South Asia, The Max Foundation
Managing Trustee, Friends of Max**



Foreword

A few months after losing my stepson Max to Chronic Myeloid Leukaemia in 1991 at the young age of 17, I was one day sitting in my living room feeling deep sadness for what would never be; a life interrupted, a bright future cut short. And I missed him so much. At that moment, don't ask me why, I had the realization that in my lifetime, I would witness the discovery of a treatment that would have saved Max. I had a strange certainty about it, almost a premonition. This thought led to overwhelming fear and turmoil inside of me: I was trying to imagine how I would feel; would it make me happy, or would it make me angry, resentful of those who would be spared while Max wasn't. At that moment I was afraid that the second possibility would be true, and I would not be able to feel happy for others. I did not want to be that person.

My premonition became a reality in 2001 when a remarkable new oral treatment was developed and brought quickly to the market. This treatment changed the nature of this leukaemia and transformed it into a chronic condition for most patients. In a strange twist of fate, shortly after, I found myself playing a key role in facilitating access to this magic bullet to thousands of patients around the world.

This book contains the stories of fifteen of those patients. These are stories of survival, resilience, tenacity, and love, and relates the journey of families at the front of the line, those who through no fault of their own, found

themselves being pioneers for one of the most inspirational two decades in the history of medicine. Without a road map but with the courage that emanates from within when a loved one receives a devastating diagnosis, the book tells the journey of each of these families, how each of them overcame unsurmountable fear, how they came together to support each other, and how they survived, 20 years later, stronger than anyone could have ever imagined.

I have been blessed with the love of these families and so many others. And for that fear I had, it turned out to be quite an unnecessary anxiety. I was not resentful, not even for a second; I have been blessed with the opportunity, I have witnessed the purest kind of love among people across cultures and geographies, and I have learned the real meaning of generosity.

Today, I feel like the luckiest person in the world and am proud to be a Friend of Max. I would like to express my personal gratitude to each Friend of Max for carrying on Max's spirit in India and beyond, building a legacy of dignity and hope.

With love,

- Pat
Pat Garcia-Gonzalez
CEO, The Max Foundation

Artist:
Pinakin Munshi
(Thane)

Diagnosed:
2007

Energy



When Ashish Poddar walks into a room there is a sort of electricity in the air, and everything pulsates with the rush of energy he brings with him. Pinakin's intriguing artwork featuring these lively Warli figures is totally representative of how Ashish can mobilize a whole room of people into effective action.

Ashish Poddar



Mumbai
INDIA

November 1995

Ashish, a tall and handsome young man of 21 years is returning home by what is known as the Mumbai Local, has a mishap and falls off the train. Taken to the hospital by the conscientious Railway Police, Ashish receives the necessary first aid. Much to their relief his worried family who have rushed to be with him, are told there are no serious injuries, and he can go home. However, there's a niggling kind of fever which doesn't go away, and investigations reveal very unnaturally high white blood cell counts. His brother and his wife do not share anything, not even with their parents but take him for some seemingly ordinary follow up. Eventually Ashish understands that he has been diagnosed with this blood cancer called CML The young lad is incredulous:

"I could not understand how and why, as I was completely a simple person with no habits as such, like drinking, smoking, tobacco not even tea and coffee. At that time cancer was a very big thing, much feared and maximum life expectancy given to a patient was 5 years. Only if you are able to find a bone marrow match, I was told and was able to get a bone marrow transplant would I have a chance of survival. Things were not in my favour as I could not find a match in my brother or sister. I was also advised to look for an international match, as at that time there was no donor registry in India. We started with conventional treatment like Hydrea, Interferon injections, Myleran, Busulfan and believe me the side effect of those medicines were so bad I can't even explain in words. It was like waiting for each day to pass and then get ready to face another."

Today almost 25 years later Ashish looks back at how he decided not to give up but with great positive energies pursue whatever path had to be taken. He heard of a trial in the US and managed to raise funds to make the trip only to find the trial was closed to patients who were in accelerated phase of the disease – yes, his condition despite the various therapies he had tried, was deteriorating. By his side was Pratibha, his college sweetheart who was steadfast in her desire to marry him. When in 2000, Imatinib burst upon the firmament of CML therapy, hope was born again but the cost of the drug was astronomical.

"Luckily in the year 2001 or 2002 I came to know Novartis is getting the medicine to India and since it's not affordable here there's an organization through which the drug would be given to patients at no cost. My case was evaluated, and I was enrolled for the same and met Viji Amma of The Max Foundation which changed everything. In the first two months of starting the medicine there was magic, all my side effects started disappearing and my reports also started improving. I was very thankful to my family who were always very supportive and hopeful of magic happening which really happened, and I was getting better. Looking at the results again my now wife decided to marry me against her family's wishes and her prayers also worked. In the year 2005 again with blessings from God and good wishes of everyone, I was blessed with a daughter."

August 2022

It has not been smooth sailing for Ashish. Looking at him today, standing tall and inspiring so many like him to live life to the full, one would not believe that he has in these intervening years progressed on both Imatinib and Nilotinib and became resistant to them and is now on the other second generation TKI, Dasatinib. He continues to direct all his positive energies into innumerable social community projects, works 24x7 supporting his family's business and is always available when Friends of Max needs his attention.

Artist:
Pinakin Munshi
(Thane)

Diagnosed:
2008

Compassion



Bidurin's whole being is suffused with compassion and one has just to meet him once to recognise that soft and caring side of him. He says it comes to him from the love and care lavished upon him by his mother and father throughout his childhood. This painting of a mother and child by Pinakin seems to symbolise all that love so eloquently.

Bidurin Chakroborty



Siliguri
INDIA

1998

Bidurin was the first paediatric patient to be enrolled in the patient assistance program. He came to us when his CML reappeared post a Bone Marrow Transplant done earlier. I have never seen a young boy more passionate and hungrier for experiences as Bidurin. Nothing could keep him down. He was always ready for adventure. Once after a rather exhausting follow up in Tata Hospital I remember him literally dragging me to a roadside Dosa Stall in Parel (his favourite I found out) so that we could have some piping hot tiffin.

"I was 9 years old when I was diagnosed. As a kid I did not understand much about the impact of the disease. But from the tension on the faces of my parents I realized something was wrong. Relatives used to come to see me, our visits to different doctors started. The most difficult experience was the bone marrow test, which at that age was very painful."

When his treatment necessitated the family relocate to Mumbai for one whole year Bidurin realized how drastically his life was to change. He missed his school and friends and his family back home.

"But I believed that this too would pass. We kept fighting as a family and kept following what my doctors were telling us to do. My Bone Marrow Transplant happened. Years passed, my health improved, and I started to live a normal life. But this was not easy. I had gaps in my schooling, my friends changed but throughout it all I held my hopes high and kept trying."

Just a few years ago, I attended Bidurin's wedding to his beautiful sweetheart. With me was Dr Reetu Jain his BMT physician. Together on the flight to his hometown in Bengal we both wondered at the tenacity of this young man, of the joy and pride both of us felt in knowing him and what an honour it was to be present at this important moment in his life.

August 2022

"I am 32 years old now, married, have a job. I had multiple treatment relapses, a severe one 4 years back. With support from family and friends, I am far better now and trying to live a normal life. I am taking my medicines regularly, there are some chronic health issues. More importantly, my heart skips a beat every time I check my regular test reports. But this has become a part of life now."

I always try to focus on the positive aspect of everything. I know there comes some dark times, when our life is not in our control, we must depend on others, and we tend to lose hope. But in those times, we need support of our close ones, who provide the much-needed warmth and positivity. I do what I love to do, I travel, I try adventure, I eat different foods. A disease will not restrict me from enjoying my life. After all, "Babumushoi, zindagi badi honi chahiye ... lambi nahin".

Artist:
Kiruba
(Chennai)

Diagnosed:
2008

Dignity



Kailash is the son of a proud farmer and works today tilling the land standing tall beside his father. There is a fierce pride in his demeanor and a quiet dignity in his voice as he shares his story with us. We could not go beyond this image of a man with his plough on his shoulder to depict Kailash's persona here.

Kailash Suresh Ingale



Nanded
INDIA

2000

22 years ago, a little boy, the son of a farmer from the interiors of Maharashtra is diagnosed with CML. His father takes him to hospitals in different towns looking for treatment. The child is traumatized seeing his father struggle. What hurts him most is the way the people in his village have started avoiding him and his family ever since they found out he has cancer...

In Kailash's own words:

"I came to know it was Cancer - the deadly disease, but then I decided to fight the cancer. I don't know from where I got that strength. My father was very supportive.

I come from rural area and here I experienced the stigma attached to this disease. The villagers' behavior towards my family and I was getting worse day by day which I can't forget in my life. I was finding it very difficult to face this situation. My family members were my support system. Especially, my father - he was so strong and could give me the strength to fight the situation."

For someone so young, there is a huge fount of wisdom in Kailash. He took a proactive interest in his treatment and interacted a lot with other patients he met in different hospitals. It is his outgoing and extroverted nature but also a deep sense of responsibility for his own well being and to not be an emotional load on his father.

"In my worst days, I saw a ray of hope through a person whom I met at MGM college in Panvel. He gave me the suggestion to get treatment in Tata Memorial Hospital Mumbai. In 2003, my treatment started in Tata Memorial Hospital. In the month of March, I started receiving free medicine from The Max Foundation. I was very happy with this. Life almost came back to normal with the Glivec and the support of The Max Foundation.

In 2008, I met one person who was going through cancer treatment and suggested him to take treatment in Tata. Unfortunately, he died soon. I was shocked but then I realized the value of my life.

The Max Foundation team helped me a lot. Whenever I visit Mumbai, I also meet Max team members who give me homely feeling. I feel like I am meeting my family members. There is so much love and affection."

To say I have watched Kailash grow in front of my eyes would not be an exaggeration. Whether when in his teens, or as a young adult or as he is now, married, a householder and a father, Kailash is the epitome of dignity that impresses everyone he meets. His quiet demeanour belies a shy sense of honour and when he lets his guard drop his eyes are brimming with laughter.

August 2022

"With the grace of GOD, I found my life partner. I have two children now. The society that was critical and doubtful about me behind me at that time have started telling me that I am so lucky to have happy life.

I had faced severe problem while searching for my life partner. People created various issues as they were aware that I am a cancer patient.

Before getting married, I had informed my wife about CML. She has accepted me as I am. She said, not to worry and I will have a long life. With her consoling words, I felt very happy. Now, I am earning my own bread and butter as a daily wage labourer and supporting my family."

Artist:

Satadipa Sarkar

(FOM City Chapter Leader, Kolkata)

Self Belief



This supremely powerful image of the Buddha created by Satadipa of Kolkata seems to be made for Parbhu... calm, composed, and full of belief in the self. I do believe this is how Satadipa sees her husband, Arindam who has also been in treatment like Parbhu for over 17 years. This connects them both in a unique fashion.

Parbhudayal Badariya



Mumbai
INDIA

A ten-year-old boy complains of not being able to see things clearly and his family tell him it must be because he's always in the sun. He remembers having typhoid and some changes in his skin colour. It took almost two years of various symptoms before he was diagnosed with CML in the year 2001 at the age of 12.

1998

Says Parbhudayal, *"I had no idea what CML is neither did my parents. My family members were deeply saddened by the news, especially my mom who got very emotional when they told her it was cancer. As for me, I am someone who is positive and decided to face this bravely as that was the only way. I believe that nothing good comes out of constantly thinking about unfavourable things that have happened to you. You need to learn to move on from the tough situations you encounter."*

The young boy was aware how strained finances were and how his family had to face many difficult situations before he could even begin treatment. They were unable to get any proper guidance and spent over six precious months just waiting in long lines in hospitals waiting to be seen by a doctor. With resources dwindling they took him back home to their village. And that Parbhu says, changed his whole life because it was their family doctor there who guided them to go and see a 'cancer specialist'.

"In my village we have a doctor who knew about a very good cancer specialist and he suggested we visit Dr Boman Dhabar. After that I met Dr Boman who told us about The Max Foundation and asked me to connect with them as he knew about my financial condition and that I will not be able to afford treatment. After I connected with The Max Foundation, I got in touch with Amma. Amma helped me with my treatment and gave me strength and treated me like I was her son."

It was in 2005 eventually that Parbhu's treatment finally started. When I meet him today, after 17 years or more, I still see the naughty, impish, bright eyed 12-year-old boy and not the calm and composed young man standing in front of me. The glint in his gives him away of course.

August 2022

"I have been taking medicine for 17 years now and I enjoy my time playing tabla and dhol at religious gatherings."

All thanks to The Max Foundation and Amma that this was possible. Today I am healthy, and it is all because of Dr Boman Dhabar. I want to thank them with all my heart. Thank you all who supported me to get fit and fine. I want to tell everyone to not remain fixed on the bad things that happen to you. The highs and lows you face are part and parcel of life you just need to learn to be positive, believe in yourself and happy and live life to the fullest through it all."

Artist:
Suresh Thottupurathu Sreedharan
(Kottayam)

Diagnosed:
2007

Love



Perhaps the purest and most unconditional emotion of them all - LOVE.

The love of a parent for a child, the love discovered by partners who decide to spend their lives together in its glow or the love treating physicians feel for their patients. Suresh's depiction of this precious emotion reflects the care Shajahan and his beloved Mumtas have always received from their doctor.

Shajahan K



Kozhikode
INDIA

January 2002

Shajahan was just 20 years old when his whole world came crashing down. Diagnosed with CML in the prime of his life, he and his family had no way in which they could afford the treatment he was advised or even consider a Bone Marrow Transplant the only cure available. In his own words, "Monetary crisis hit my family and I was totally broken".

August 2022

Shajahan and his lovely wife Mumtas, also a CMLer present the perfect picture of love – against all odds. I remember how the smitten young lad would wait with bated breath to meet with his lady love at the physician's clinic and how we had to play Cupid as well to convince Mumtas (and her stern disapproving father) of his honourable intentions. Says Shajahan, as he recounts his 20-year-old journey as a CML patient:

"With the help of The Max Foundation, I was provided Glivec which really was a great relief both mentally and financially. I take this opportunity to express my gratitude toward The Max Foundation for making my life possible. I am still getting medicines from the program.

My doctor Narayanankutty Warriar Sir helped me in finding my life -partner Mumtas - she is also a CML patient taking treatment under Dr. Warriar. We are really blessed to be a part of The Max Foundation, as we both are getting our medicines with their help. I take this opportunity to thank all my well-wishers who always cared for both of us.

I always wanted to serve the society. I have also been actively supporting Friends of Max.

Now, I am involved actively in social activities like Cancer Awareness campaigns, blood donation drives and other activities which educate people about healthy living."

Artist:
Riya John
(FOM Mumbai)

Positivity



Five-year-old Riya drew this for us perhaps a year after her father was diagnosed with CML. The power of positivity that emanates from this image bellies the young years of the artist. We find this the perfect representation of Leena's calm and positive attitude with which the young mother faced her diagnosis all those years ago and which allowed her to arrive at where she is today – in complete control of her life and her CML.

Leena D'Silva



Vasai
INDIA

February 2002

36 years old, mother of two children and the axis on which her household runs – Leena is told she has cancer. It is not surprising that she herself, being the kind of woman she is, is instrumental in ensuring the symptoms she has felt are not ignored and medical advice is sought immediately. That's her with her totally no-nonsense attitude.

"Given my mixed and diverse religious background, I am fortunate to celebrate both Diwali and Christmas."

It was during the festive season of 2001 when the family got together to make sweets and savouries, I began experiencing sheer tiredness, fatigue and absolutely had no enthusiasm in doing anything. As against how I saw my mother who is much older than me, full of zeal effortlessly completing the given task at hand. That was the first time I realised something is not right. This continued for some time and with every passing week it became worse. Finally on 11th Feb 2002, I did a blood test and fortunately or unfortunately, I saw the outcome myself with WBC being 1,98,000 and result being CML. I knew what it meant..."

Leena has titled her story thus – The Journey from Cancer Patient to Cancer Survivor and she was personally at the helm steering it the right way. With her equally calm and unflappable husband by her side Leena made sure she was under the care of one of the best oncologists to whom she credits not just the timely and appropriate management of the disease but also for infusing her with confidence and the courage to face the treatment that lay ahead.

"I told myself, I must fight this out for my two kids who were 12 and 8 at that time. My daughter was studying in a boarding school away from me. I called her back home so that she could be with me. My parents came to stay with me for first few months during the initial treatment which provided me with the necessary emotional and physical support. My younger brother and sister stood by me and helped me carry this cross."

In the first phase of treatment Leena tells us it was Hydrea tablets followed by Interferon injections. The side effects were drastic, but with her husband by her side she survived the challenges involved. Being Interferon intolerant enabled her to immediately get into The Max Foundation's assistance program.

August 2022

"If I am alive today living a decent financial life, then the credit goes to "The Max Foundation". The Foundation has also helped cancer survivors find the emotional support through their regular seminars. They have created a forum Friends of Max where survivors can share their stories and top oncologists in town share their expertise so that a ray of hope is found every time we meet."

One mantra that I have kept saying which my father has taught me is, "Day by day in every way, I am getting better and better". Indeed, with positive attitude, family support, Glivec medication and right food intake, I am feeling strong and healthy."

Artist:
Durgesh Saini
(Delhi)

Diagnosed:
2008

Courage



It takes immense courage to take flight into the unknown, especially when carrying the excess baggage of two cancer diagnoses. But then that's what Shova possessed in plenty. Durgesh's portrait of this single minded and focused bird for flight is pure courage – pure Shova.

Shova Karki



Kathmandu
NEPAL

If you ask me how to spell courage, I will say like this:
SHOVA

April 2002

A vivacious and free-spirited young woman of 26 years is told she has a fatal condition called Chronic Myeloid Leukemia. A battery of tests is performed on her slim and frail body, and she is subjected to the rigors of aggressive treatment. And what does she have to say? This:

"There is an old saying "life is a journey". It is true because there is hardly a life that has not seen its ups and downs. We all sometimes experience the highs and the lows - of happiness and sorrow, but either way, the destination is the same with both. Similar is the story of my life, where I have been comparing the cancer present in my life with 'bitter gourd', a vegetable that is bitter, yet fruitful in many ways.

I grew up in a lower middle-class family, struggling with my family's financial situation. I had just completed my graduation and was preparing to give a new direction to my life with a ray of hope to myself and my family, I was unaware that I had leased my body out to a chronic disease. It is said that when there is disease the body gives out signals which perhaps, I hadn't cared about at that moment but on hind sight can realize I might have known."

So much wisdom in one so young.

The aggressive treatment took its toll not only mentally and physically but also financially. Looking for treatment options on the Internet, Shova read about Imatinib therapy and the patient assistance program by The Max Foundation at Patan hospital and began treatment there. In her own words:

"Soon my health report started showing improvements. However, the side effects did not stop troubling me from time to time and after taking the medicine for about 11 years, at the end of 2014, I stopped the medicine, and I am still away from CML till today - on Treatment Free Remission"

But cancer was not done with our Shova and in 2019 she was diagnosed with Breast Cancer.

"The treatment procedure this time was a bit different from the previous one. I didn't want to go for treatment because I was afraid of the side effects and also mental pressure on how to explain to my family about the disease, but I had no choice. The journey was not easy, but it was not impossible either. There is a basic mantra "accept the reality", and yes, with that mantra in my mind, this difficult journey of mine turned out to be a lot easier than expected."

August 2022

Shova shares her insights and learnings from her cancer experiences.

Cancer turned out to be fruitful for me.

-The power within me was identified.

-In the past, cancer was limited to knowledge of a word, and it was compared to death. But now I have a lot of knowledge about cancer.

-I figured out my goal in life to become a social worker and to serve people with diseases like myself.

-I have been able to go abroad and participate in different cancer-related conferences, and gain mass recognition among different people of the cancer community.

-Probably because of the journey with physical as well as emotional pain, I discovered a writer within myself by putting down emotional things on a paper.

-Except for the family and a few friends, I found out that all other people who claim to be there for you when in need are just a delusion. Once you get sick and are in actual need, you lose everybody.

-The destination of life is death, and as it is written in everyone's story, I have come to know that it is just foolishness to stop living your life in fear of death.

-Cancer is no longer monstrous and is curable if detected and treated in time.

-Cancer is still treated as a curse in many places, public awareness is still needed.

-The treatment is not simple; however, it is also not as difficult and impossible as we think.

Strength

Artist:

Renuka Lal

(FOM City Chapter Leader, Delhi)



We could look no further than this image to portray Sohag's saga of strength and sustained efforts to bring his life back on track after his diagnosis. Being a care giver and a mother herself it is no wonder our artist Renuka could express this emotion so effectively.

Sohag



Dhaka
BANGLADESH

September 2002

Just a week short of his 30th birthday, Sohag, after doing brilliantly in his Master's from Bangladesh Agricultural University was all set to accept an offer of a Fellowship for pursuing his PhD degree. Having always been very fit and of an athletic build, Sohag was perturbed by an unexplained weight loss he had been experiencing and an overwhelming feeling of weakness. Attributing it to his arduous research routine he had not been too concerned. A friend however insisted he seek some medical advice and in Sohag's words,

"Diagnosis: CML. I didn't know what CML was, but the doctor told me it is a blood related problem, don't worry there is a treatment! I had gone through the internet and finally I realized that it is blood cancer, and I couldn't accept this as true. I went to Dhaka to visit another haematologist to confirm the diagnosis, but I got the same result. He suggested chemotherapy and again I couldn't receive the message in a positive manner! I was alone with my thoughts on what I should do now. I didn't inform my parents about my illness as I was afraid the shock might kill them! At that time, I felt very helpless and cried a lot in secret. After one or two days, cautiously I informed my parents about my illness, requested them to be calm and pray for me. In the meantime, the news spread to all my neighbourhood, and everybody came to visit me as they believed, I would leave the world very soon. The pain and fear I felt then was unbearable. I thought, I must fight..."

Now that I know Sohag (having met him ten years after his diagnosis and spoken to him only on the phone till then) I am not surprised at the strength he garnered to equip himself with for this fight. He went to India, met the best doctors and understood all about the treatment available. His family sold all they could to raise the money to buy the miracle drug that would turn his fatal cancer into a chronic manageable condition.

"We had nothing. I was praying a lot, asking God to give me strength to face what I had to live through. At that moment, again I spent a lot of time to search through internet for any donor or charitable organization that could help me. Here I came to know about a support program by The Max Foundation, I applied there for assistance. Ten to fifteen days after application, when I was sitting alone on the bank of the Brahmaputra River, surprisingly one woman (who later I came to know as Amma) called me over phone from Mumbai, India and told me, you are eligible for the patient support program and asked me to send some necessary documents immediately. I forwarded those documents and got approval on January 2003 and that's the moment that truly changed my life...!"

August 2022

And indeed Sohag has only gone from strength to strength - he completed his PhD, found a deeply satisfying job, got married and is blessed with a daughter of thirteen years and a son of five years ; though he says, it was unimaginable in 2002.

"My illness gave me more than enough strength to keep going, I have a strong desire to work, and I have the spirit to drive ahead! I established a patient support group in Bangladesh in 2013 in order to provide mental support to the affected family, create awareness and reduce stigma on cancer and developing a network of support and care."

"God bless you all the members of The Max Foundation.... You are really making a change in our society!"

Artist:
Prashant Kumar
(FOM City Chapter Leader, Patna)

Resolve



Prashant whose mother Smt. Bacchi Singh was diagnosed in 2002 sent us this image he had created of his son a few years ago. He has always shared how his mother's resolve to go on with her life despite her diagnosis has inspired her whole family to only look ahead.

Aziz Ur Rehman's resolve in making sure his diagnosis doesn't come in the way of his son's future is reflected so perfectly in this image.

Aziz Ur Rehman



Gujrat
PAKISTAN

March 2003

When young Aziz was diagnosed with CML, his father was forced to sell the family-owned ceramic factory inherited from his uncle. Aziz Ur Rehman hails from a city named Gujrat in Pakistan. As he shares, *"I am a potter by profession. I have done my BCom and Masters in Punjabi. Post my final BCom exam in the year 1996 I joined the ceramic factory which was owned by my uncle. We were a known name in the ceramics industry in Pakistan."*

His uncle passed away leaving behind a debt-ridden business which Aziz and his father eventually turned around but the huge cost of the treatment for his cancer forced his father to sell the factory. With great difficulty he was able to avail of the medication at no cost after being told about The Max Foundation's access program at The Shaukat Khanum Hospital by a physician friend.

Today, Aziz himself is father to a son who was born 12 years after he married his lovely, supporting wife. It has not been easy for him to continue with his treatment what with the vagaries of the political climate and erratic health policies in his country but that has not weakened his resolve to live his life productively and support his wife and son to the best of his ability.

"I have three brothers and three sisters. I got married on 15th February 2002. With God's grace after 12 years of marriage, we had our son. My son has Cerebral Palsy, so he is unable to speak or walk. He does say Ammi and Abba clearly now so we have this hope that he will be able to talk soon."

Artist:
Amlan Shet
(Hooghly)

Diagnosed:
2006

Perseverance



Amlan's simple yet beautifully proportioned sketch of a peacock's tail with its beautiful eyes perfectly complements the perseverance with which young Karan has gone about achieving his goal of becoming a professional Rifle Shooter – a dream he had set his eyes upon when he was a young boy barely after his diagnosis.

Karan Vyas



Vadodara
INDIA

November 2003

A little boy and his parents attend a Friends of Max Patient Support Group for the first time. He is a sweet and gentle soul, his parents a little wary, a little hesitant. Soon the atmosphere at the Cancer Hospital in Ahmedabad, as comforting as the mild early winter sun that morning, envelops them in its warmth and they come forward to meet and interact with the others. I can never forget that first hesitant hug little Karan gives me nor the worried visage of his pretty young mother.

"I was 10 years old when I was diagnosed with Chronic Myeloid Leukemia (CML) when I was in 7th standard in school. I did not know what CML was when I was that young; at that time I just saw my parents and my family members crying and as a child I was shocked and surprised why I was making my mom so sad. When I asked her what the reason was, she did not speak a word. I knew that there is something very wrong about my health when they began to take me to see many doctors. One of them had told my parents about a new medicine which everyone called the Magic Bullet which can successfully work against CML. I started the oral medication and that was Glivec made accessible by the patient assistance program managed by The Max Foundation. This was the time when I met the most wonderful person in my life Viji Venkatesh my Amma and The Max Foundation, which is supporting patients like me throughout their lifetime fight against CML. My blood counts came under control, and my family got a sense of relief that CML can be fought."

Much later Karan told me how he himself understood all this only when he was older. His health remained frail, he had some severe side effects and had to miss a lot of school during those initial days. Eventually with the care his parents took to keep him compliant and his own good adherence his CML was brought under control, and he resumed school. He cleared his Board exams with merit and in 2011 completed his Diploma in Mechanical Engineering. There was another dream this young lad whose middle name appeared to be Perseverance wanted to fulfil which he went about doing with great elan. Even a diagnosis of Tuberculosis could not deter him from this.

"I had my interest towards shooting since childhood but back then I was doing it just for fun. In 2015 I trained in Professional Rifle Shooting sports. I had something inside me about shooting I believed, and God proved it by encouraging me with the taste of success. I won the District as well as State Shooting Championships. And I want now to get into the Indian Shooting Team - I want to compete in the Commonwealth Games and then The Olympics. In my six years of Rifle Shooting, I have won twenty-five medals till now."

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So that little Karan, today has completed his BSc in Sports Coaching and presently is in the UK completing an MSc in Sports Performance Analysis. If this were not enough, Karan is also pursuing Certifications in Gym Instruction, a Diploma in Personal Training & group training as well as Nutrition and Exercise referral.

Says Mr Perseverance *"So, today, my life is now all about Sports and Fitness, and I never have and will never let CML become the hurdle in the way of any of my endeavours."*

Artist:
Suresh Thottupurathu Sreedharan
(Kottayam)

Diagnosed:
2007

Grace



There is something about Rushmie that is grace and graciousness personified. All the years we have known her it is this facet of her persona that has stayed with us. Throughout her journey after being diagnosed and as she refashioned her life as that of a caring and determined patient advocate. How beautifully Suresh's image of the graceful swan matches Rushmie's own demeanour.

Rushmie Fernando



Kelaniya
SRI LANKA

January 2004

Rushmie Fernando, 63 years of age, a CML patient and a Patient Advocate from Sri Lanka is the embodiment of grace. Diagnosed when she was in her early 40s, a professional career woman, she tells us how this life altering diagnosis affected her life.

"With constant pain underneath my left rib cage (later found it was an enlarged spleen) and losing considerable weight, I was diagnosed with CML in 2004. I felt tested both mentally and physically. Being a career woman, I had to revisit and evaluate several facets of my life. The diagnosis affected my perception of time. I had never thought of the length of my life until then."

Glivec, she says, brought to her thanks to the access program and The Max Foundation, was simply too good to be true. *"After six months had passed by and I began to regain my sense of normalcy, I started to gain strength and felt more like myself. I was actually amazed at the confidence these months had built in me. I never took life for granted from that juncture; I value every second, every minute and every day and try to make the most of it. Ever since my diagnosis, I made every effort to make myself available to CML patients who need help at the time of diagnosis. I am happy even if I can comfort them with a single kind word."*

And how graciously Rushmie has kept her word.

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"I joined many voluntary groups to help cancer patients and we spend much time at the country's main cancer hospital as well as its Hospice. My favorite work is spending time with clinic patients. Other than serving them with a snack and a beverage, I love the little chats I have with them, after all we speak the same language. I want to share my experience and story with them and hope to give them enough courage to move on. Majority of them come from the villages and are poor in their finances. We take it upon ourselves to guide them to various charities and help them out in many ways possible."

Artist:
Anushka Indurkar
(FOM Aurangabad)

Resilience



Bright and bold as sunshine, no matter how tough the terrain; if you are resilient, you can weather any storm. Bubbles' philosophy and the truth she has lived by can also be summed up by these words and this image.

Anushka, the artist is the young daughter of one of our physician partners Dr Indurkar from Aurangabad and this powerful image was drawn by her at a support group meeting in the city.

Bubbles

November 2005

A feisty, bubbly, and irrepressible 19-year-old medical student, let's call her Bubbles, is diagnosed with CML. And what does she do when she finds out – let's hear it from her ...

"So, when I, a second-year medical student, who had none of the so called "BAD" habits or any family history of malignancy, found out that there were these terrible cancer cells surfing in my blood, my first instinct (as expected) was denial (obviously followed by rest of the stages of grief, with all the dollops of drama involved and expected in a middle-class Indian family). My diagnosis was actually what we call a CHANCE diagnosis in medical jargon – something which was discovered by luck. Falling ill (usual culprits like fever, body aches etc.) in second year of MBBS is actually considered normal given all the torture (physical, mental, emotional) medical students have to endure. But for me this frequency of falling ill was slightly more than the rest of my colleagues, urging my hospital senior resident to order a battery of tests to find out the cause (in hindsight I think he was just trying to get rid of me for good). But poor guy did not expect what the blood test would reveal, nor did the rest of my family and friends. Voila – extremely high number of white blood cells.

What followed was usual protocol – loads of blood tests, a bone marrow biopsy (ouch that hurt) and once the diagnosis of CML was confirmed, then began my tryst at Tata Memorial Hospital, Mumbai."

Let not this breezy style and adorable sense of humour fool anyone – One look at those bright and expressive eyes and a few minutes after she walked into my office for the first time, I knew this was her coping mechanism. It was obvious what this blow meant to a young woman who was in her second year of medical college and whose parents and siblings were worried sick for her. Her strength lay in her cheerful disposition. She worked her way through all the conflicting emotions, the fear, the questions and accepted the diagnosis prepared to take what was coming on her defiant chin.

"God/karma/kismet decided to smile at the young me, and we found that a miracle drug has recently been launched in the market and is now being offered to patients of CML as an alternative therapy to bone marrow transplant. It was like manna from heaven (my first thought after I heard about it was: I will not have to go BALD. Like I said, late teenage thoughts, no sense of priorities in life, sigh).

In 2005-06, a box of Glivec cost around ₹ 1 lakh and for a family of five, with one earning member and four dependents, it seemed like an impossible task and whatever little hope we had was slowly fading away.

Enter The Max Foundation with Viji Venkatesh (my very own wonder woman) and Ayesha (my wonder woman 2.0). With their immense help I was able to get my life saving miracle drug free of cost for a very long period."

I have seen the long gruelling hours and the back breaking hard work Bubbles put in month after exhausting month to finish her medical school and then go on to train in her choice of a special field . She would take my sermons on good adherence and compliance very seriously and come to me with a guilty face and endearing looks to be chastised suitably when she defaulted. She brought sunshine into our office, did this bright young girl.

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"I am now 37 years old, a practicing Radiologist, been on Glivec for 17 odd years and by God's grace – in remission. My CML journey has been largely smooth, with bits of trials and tribulations here and there, but all in all I am a thankful person that my diagnosis was made on time, I had access to world class healthcare and miracle drug Gleevec was made available to me. Most importantly I am thankful to my family, friends and everyone at The Max Foundation who work selflessly for lakhs of patients like me.

Let us hope that science can progress further faster, and there can finally be a cure for not just CML but all cancers (cheers to that)."

Hope

Artist:
Deep

Diagnosed:
2008



Deep sent us this depiction of Hope created by her to go with her own inspiring story.

The lantern of hope lighting the difficult path ahead of her so she could achieve her ambition. To be able to study and qualify for the Civil Services so she can serve her country and countrymen to the fullest of her capabilities.

Deep

June 2007

Deep, a bright young teenager with the light (like her name Deep) of hope in her eyes is diagnosed with Chronic Myeloid Leukemia. Her father who runs a small shop in a little town is forced to take loans to arrange funds for her treatment and when that is no longer possible, they must sell Deep's mother's jewellery. Her parents assure her they will do everything to keep her well but in six months they run out of money and Deep's treatment comes to a halt.

Deep tells us about the Angels of Hope in her life who at every step lit her path to recovery.

"When you lose hope and life is in darkness with all doors shut there is always a ray of hope brought by an Angel to rescue you. My name is Deep, age 32 and I look back to 16 years when ago my life was turned upside down. I was diagnosed with CML I was just a teenager, full of dreams in my eyes. My dreams were shattered, the explosion so loud in my ears. My parents told me they would do everything to save my life. The doctor told us the treatment will be expensive and I will have to be under medication my whole life. My father being a shopkeeper with hand to month income realized how impossible it was but still, he never lost hope. With loans from near and dear ones and by selling my mother's jewellery we started my treatment. After 6 months of treatment, we did not have a single penny to buy any more medicine. My health condition became so bad I had to see my doctor. Like an Angel of Hope then my doctor gave me 10 days sample medicine and talked about The Max Foundation which supports CML patients and provides free medicine under their program. He arranged for me to register, and I got medicine at my hometown."

The light of hope began to glimmer once again in Deep's eyes and reassured by her parents and the doctor she began to pursue her dream of studying to be in Public Service. At The Max Foundation we encourage all our patients to become members of the Patient Support Group Friends of Max and Deep became a quiet but regular presence at such meetings taking inspiration from others, becoming stronger and inspiring others with her single-minded pursuit of her dreams.

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"My parents and doctor always encouraged me to live life like nothing happened to me. They motivated me to study well and achieve anything I wanted. In my journey Viji Amma and Sudha Didi of The Max Foundation always counselled me to do better in life. I am always inspired by them to serve people."

I always wanted to be a bureaucrat. I completed my graduation, my MSc degree and pursued my PhD. I started preparing for Civil Service and got selected in the State Public Service. After 2 years of difficult training, I was successfully posted and got a chance to serve the people, work for people. Now I am happily married.

The Max Foundation and others in Friends of Max gave me hopes to live a better life. Angels like my parents, doctor, Viji Amma, Sudha Didi and so many came in my life and showed me the ray of hope to live a better life. I always feel grateful to them. So - 'never lose hope'. They made me capable to buy my own medicine. The Max Foundation not only supports life also transforms life."

Artists:
Arjun and Firdaus
(FOM Pune)

Fearless



Two young boys whose beloved uncle was diagnosed with CML found the care their uncle received akin to the protection the people facing the wrath of Indra received when Krishna held aloft Mt Govardhan over them. In this beautiful image with every detail highlighted we see young Abhishek's fearlessness too as he went about facing and protecting himself from the rigors of treatment that began for him at a very young age itself.

Abhishek Pandey



Allahabad
INDIA

August 2007

I think young Abhishek when he came first to the Max Office in Mumbai was accompanied by an uncle or older cousin. A shy, bright faced, and vulnerable looking 13-year-old one just wanted to gather close to the heart and comfort. Fatherless since the age of 4 and brought up by his mother who struggled to give her little son what education she could with the meagre resources at her disposal. And in the midst of an already challenging situation came the news of his cancer.

"I was in my 8th grade. Back then, we did not even know what CML is. When my mother was informed about the diagnosis everything just stopped in my household. We were not financially stable and then to add to this I was diagnosed with a cancer! Treatment would be a big financial burden for us. At that time our family and relatives thought that it will be impossible for us to afford the treatment. I could only see the end of my life as none of us could understand what has happened and how I would be able to continue my life. My mother with the help of our relatives collected money and then we left for Mumbai for treatment. We went to Tata Memorial Hospital and then the doctor there told us about this medicine that I was supposed to take. Understanding our financial status, he then guided us to The Max Foundation and how they help those who could not afford medicine. That is how we were able to get the medicine. My family members finally had the courage that I have found a way to live."

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Abhishek today is the voice of many patients like him who come from villages and little towns in the interiors of the country. He will never refuse a request to share his story be it on print media or on the radio or for sharing on international platforms. A true patient advocate who tells everyone to fight the fear.

"I would like to thank Novartis for giving my family and I another chance at life. I have been with Max since 2007. I am healthy now and able to live my life like anyone else. Now I am working on improving my financial condition. I am teaching kids and also studying myself so I can get better work opportunities."

My message to everyone who is going through some struggle in their life is - The challenges that we face in life are to work on our mistakes and to improve ourselves as well. Therefore, we should never run from these challenges but rather we should fight them till the end. These challenges are like teachers in our life and they help us choose the right path in life."

Running away from problems is easy and all these struggles are like life's way of giving you an exam. Those who are afraid do not get anything in life, world is at the feet of the one who fights. Apart from The Max Foundation, I want to give all my love to Amma who has always encouraged me to look ahead without fear."

Artist:
Sudipa Das

Diagnosed:
2013

Purpose



Single minded purpose in life – this is surely what leaps out at us from this image created by Sudipa to go with her story. Eyes focused ahead, head held high and always moving ahead; that's young Sudipa through and through. She makes us proud.

Sudipa Das



Midnapore
INDIA

January 2013

9-year-old Sudipa is diagnosed with CML. Her parents are told they need to take her to Bombay and show her to a doctor in Tata Memorial Cancer Hospital. For her parents the very thought of traveling from a little village in Bengal to an unknown city across the breadth of the country is daunting. The little girl is frightened out of her wits. Ever since she found out she was 'sick' she has stopped going to school and stopped meeting her friends. Now she is here in this big city and because all the money her father borrowed for the tickets and treatment is gone, they are sleeping on the footpath outside the hospital.

Sudipa shares her recollections with us -

"I was 9 years old when I diagnosed with CML. I was very young, and I didn't know much about this sickness. I only knew that I have got some big disease and I used to be scared all the time. I never used to talk much, nor do I remember playing with my friends. I used to stay quietly at home and did not want to go to school. I remember attending class once a week. At times, my friends used to approach me, but I didn't feel like spending time with them."

In Bombay the situation was getting worse. Sudipa's health deteriorated and living in the open in those unhygienic conditions did not help. Succour came in the form of guidance from the Tata Hospital Social Service Dept. who helped complete formalities and arranged their stay at a Dharamshala nearby. Two months of intensive treatment and then they were back in their village. Once in every three months they had to return for monitoring and collecting the medication. It is moving to read how the little girl eventually came to terms with her diagnosis and the treatment protocol.

"My parents tried very hard to be regular with the visits to the hospital and the Max office in Mumbai. Meeting the Didis there helped me a lot. It was only after some time- I must have been 11 years old by then when I began to pay attention as they explained to my parents like they did every time how to manage my CML - I understood that even though it is blood cancer but being regular in taking the medicine and seeing the

doctor without fail when called for follow up can help in keeping my disease in control. This helped me to understand my health status. I started taking my medicine on time. I was able to get back to my school regularly. I realized that two years of my life had been wasted denying the reality. Everybody around me wanted me to come out of stress but I was the one who did not make the efforts."

We saw the difference. Sudipa grew in confidence and was less shy with us. Every visit she would bring some handmade gift and a tablecloth she embroidered herself is our prized possession. Sudipa was growing into a personable young woman. She took her CML treatment protocol very seriously and even decided not to opt for a Nursing Course she was keen on because it would come in the way of her follow up. The way she has taken charge of her health is exemplary.

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Undeterred by all the challenges that came in her way Sudipa has remained focused and purposeful and is an inspiration to countless young adults facing a similar diagnosis.

"Seeing I was struggling to decide on a course to take up after my school, my mother and father suggested I study Sanskrit and admitted me in college. Now my dream is to do M.A. in Sanskrit and then a PhD also so I can be a Professor. I want to move forward in life like this."

"My mother and father are my inspiration. I am also aware the difficulties others like me would have been going through to follow a career of their choice and become a doctor, an engineer, a nurse or a successful businessman while they are on medicine. I keep the same spirit alive to reach such a level of satisfaction in my chosen career despite my CML where my success story will be shared with other CML patients."



Living with Hope & Dignity





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Together we share & learn

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