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LIVING WITH CML

Patient stories to help better understand
daily life with
Chronic Myeloid Leukemia (CML)

CML
Advocates
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The global network for
Chronic Myeloid Leukemia
(CML) patient groups



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This is the story of Parameswaran PS, a blood cancer (Chronic Myeloid Leukemia - CML) survivor.

He was diagnosed in February 2004 and was on standard medication first-generation TKI Imatinib for CML but developed resistance and underwent a bone marrow transplant in November 2006.

He lives a life of "Dignity and Hope". He shares his testimony of hope, faith and trust that helped him to cope with CML.

He is a trustee with Friends of Max, a patient support group organization for CML & GIST (Gastro-Intestinal Stomach Tumor) patients and their caregivers. Param is also a member of the CML Community Advisory Board representing the Asian region.

He represents India and hails from the south of India belonging to the state of Karnataka and lives in the city of Bangalore. He volunteers for various cancer care activities in his region.

Parameswaran PS holds a bachelor's degree in Chemical Engineering with a Supply Chain Management Master. He is an experienced Senior-level Executive in Operations & Supply Chain Management in Pharma and Life sciences.

Parameswaran PS lives in Bangalore with his family: his wife Ramalakshmi and two daughters, Sangeetha and Swetha.



Param with his daughters



Param advocating for CML

My story living with CML begins in February 2004, when as part of the annual routine check-up I was diagnosed with chronic myeloid leukaemia. The routine blood test is part of the annual medical check-up at the place of my work where it got diagnosed. There were no symptoms at all and if not for the routine blood check up it would have gone unnoticed.

My initial reaction to the diagnosis was shocking and my career was at its peak then and was handling critical projects. But I realized that my body was affected, not my mind and soul, and that is wherein found my wisdom and strength.

On initial diagnosis, I decided along with my wife not to lose hope. Yes, it was shocking to get a disease of this dimension and intensity but wisdom prevailed in me as basically being resilient with my emotion. I developed this strong hope and faith that my mind and soul do not have CML. That increased the confidence to fight this disease.

Thereafter I was more blessed to see there are medicines to keep this disease under control which further enhanced the confidence to fight the disease out. Along with the above I was introduced to patients having CML and their testimonials further strengthened my hope and faith in coping with the disease. Cancer brings financial, and emotional fears for all those who get diagnosed.

This is a vicious cycle and either all or one of them causes stress to patients and caregivers. Here most of the battle is fought on losing ground.



"I recommend none of them can impact the patient and caregiver if we make up the mind to fight this disease with mental therapeutics.

I strongly recommend patients and caregivers to note that the first three letters of the word "cancer" are "can".

*It clearly says **we can!** This will replace the fear in one and all thereby provide the opportunity to cope up."*

As said, at my initial diagnosis I was introduced to fellow CML

patients who were on standard therapy and having a very good quality of life. Seeing them my confidence increased and I also took up to be a lead patient advocate and became a hard-core volunteer to a CML NGO and thereafter being in global and regional hubs representing India. Patient advocacy has been in my dreams and I strongly believe that this can bring a difference to the patient community, caregivers, health-care professionals and pharma companies.

The patient voice being heard is what I like in advocacy!

Patient advocacy has helped me on various fronts and I also provide support to many other fellow patients and their caregivers by sharing my testimony which has improved their quality of life as well. The bone marrow transplant and going through the process as each stage was life-threatening and getting successfully out was the worst part of my testimony.

But with my strong belief in my mind and soul not having the disease helped me to pass through this difficult phase.

But I showed endurance throughout this period. I am proud to say I got fantastic support from my wife and children, the employees of the company I was working at that time, which further cemented my endurance.



"Develop confidence, the kind of confidence that leads to endurance and courage. You shall develop the power of concentration which will enable you to exclude all thoughts except the ones which are associated with your purpose."

"Cancer or any predicament one faces in life can initially be a setback but hold your ground, become aware and raise consciousness."

When cancer gets diagnosed, I had a life of hopes and wanted to live. Through hope, I conquered my fear of cancer and turned a life of tragedy into a life of triumph, a mess into a message, fear into faith and a test into a testimony.

One example of hope I am sharing during my predicament

days:

Post bone marrow transplant, it was one of my trips to my hospital along with my wife for a routine check-up. Unfortunately, the donor-cells in my body were only 56% and my cells were 44%. The results were not encouraging and doctors were also perplexed.

On our way back while waiting at a railway station, my wife was in deep worry and tears continued to pour on the news of this percentage of cells and I tried my best to convince her by giving her hope. I told her that with our firm belief we have cruised till here and we shall win this war sooner or later.

In this situation, there was a gentleman reading a book on our bench where we were sitting and he saw us and called my wife and said:





"Dear sister, I see that you are coming from the cancer hospital as I see your husband with his masks, etc. and must be out for some treatment. Though I do not know the status of your treatment, all I can say is don't lose hope because the Almighty above has some best plans for you and your husband.

Be rest assured that everything will fall in place and your husband will be healthy. I shall pray for you and your husband."

H.O.P.E - Helping One Person Everyday

Following visits, doctors found a simple method to ensure my donor cells grow and with that procedure, in a couple of weeks I got a strong reaction on my skin that followed with 100% donor cells in my body which was a miracle.

The person who approached us, reassured on the word hope and faith. His selfless time engaged to give us the strength to face life battle kick-started the hope within us and started a chain of positive energy. Hope is contagious!

It is never too late to start making the right choice. I am glad he took the time to speak to my wife. His soothing words of assurance made a difference.

You never know the difference you can make in a person's life. I decided to be bold, compassionate and a "hope dealer".

Inspiring CML patients.

When the news of Cancer was broken during the peak of my career in February 2004, I was knocked down for a moment but found wisdom within myself of not losing hope, faith and trust I had in me, my family and treating doctors. I realized my mind and soul are not affected by leukemia but it is my body and has every right to fight this out. This is how I found the wisdom of the world within me.



"World within is a practical world of power to generate courage, hope, enthusiasm, confidence, trust and faith by which they are given the fine intelligence to see the vision.

That vision resonates as

I Can, We Can

A quote I believe - Day to day, I try not to focus on what my disease is doing, I would rather focus on what my life is doing and then find out where the disease fits inside that - otherwise you become preoccupied with just living to die rather than the

Cancer resonates and recreates fear in the individual as well as the caregivers. The fear creates a cloud in one's mind and hides the sun of the individual.

Thoughts of courage, power, confidence, hope and faith shall expand the mind which in turn eliminate the cloud thereby allow the sun within us shall shine leading to better manifestation.

When human beings are frightened they are not in harmony. It is fear that creates defences and consumes a vital part of one's energy which could be instead be used in positive ways. Confidence comes from inner strength, from the inner conscience that constantly judges one's thoughts, feelings, desires and motivations.

Positive thoughts destroy negative like light destroys the dark.

During my entire phase of celebration with the cells, I was in complete harmony inside me. No element of doubts as "WHY ME".

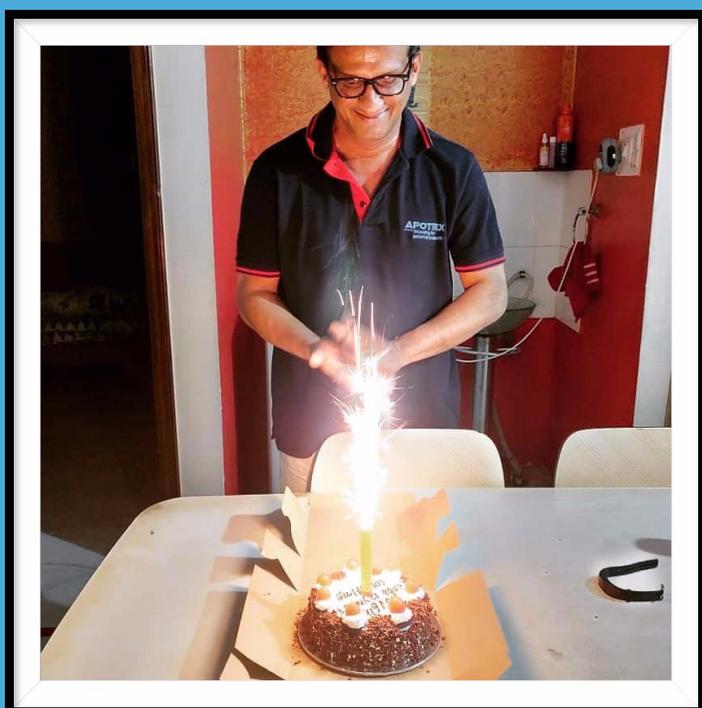
"Our active collaboration is essential in almost all forms of medical treatment. It is particularly vital in the case of chronic diseases or conditions for which medicine has no cures.

In such cases, the quality of your life may greatly depend on your ability to know your own body and mind well enough to work at optimizing your own health within the bounds, always

unknown, of what may be possible."

I strongly believe that yoga and meditation should be practiced. Yoga helps in fine-tuning the body and shaping and strengthening the muscle tissues etc. and meditation helps in shaping and strengthening the muscles of our brain and mind, and would refer this as a mental therapeutic approach.

The extremely important aspect of doing yoga and meditation is being mindful which enables to be in the present and that's the power we learn from the breathing.



"We breathe the air in the form of inhaling oxygen and exhaling carbon diode. We can realize this while we are mindful and if we are not mindful, breathe becomes air."

"This mindfulness is a great healer for all, it helps in stress reduction and eliminates pain. Life will manifest to see harmony and bliss which restores the smiles in one and all."

"Celebrations of cells: hope, faith and trust"

Hope - I had hope in my own self and never felt hopeless. I realized that being chosen to have this, could be to make a difference in many other lives with my testimonials and restore the lost smiles I never felt hopeless.

Faith - I have a strong faith in the universal power that governs us all and I am a strong God-fearing person. I allowed the faith to do the needful and never cursed my predicament.

Trust - I had complete trust in my family, treating doctors and medicines I am taking, thereby never ever googling to see the kind of treatment. Google can provide some statistical information but it is important to trust your inner circle of family, doctors and network.

HOPE

Help One Person Excel

Help Other People Excel



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