

# Living with Hope and CML

## MY CML STORY - By Joannie Clements

Joannie lives with her husband Jerry in Costa Mesa, CA on the Pacific Coast of the USA. She has 3 children, 5 grandchildren and 6 great grandchildren. She is retired and has been a passionate CML patient advocate for nearly 20 years and the founder of CML Busters Family Support Groups in 2003 which continues to operate today.

In 2019, she and her husband established the "CML Buster Foundation", a non-profit organization which will expand their mission: to empower CML patients and their families and improve their quality of life in the USA. She functions as CEO, Board Chair and VP Mission.



Advocating in our Capital



12-25-2001 Before CML Diagnosis

Joannie's journey began December 28, 2001, at the age of 59. A blood test revealed a severely elevated white blood count of 357,000, a spleen the size of a football, a 26-pound weight loss and dropping fast! Immediately admitted to the cancer floor in hospital, she was dying, scared, and confused.

On the first few days of her 10-day hospital stay, there would be a lot to process for her husband, their family and herself. Jerry held her hand through 2 bone marrow biopsies, hourly blood tests, and watched as the nurses and doctors hooked her up to blood transfusions and multiple IVs filled with mysterious and, hopefully, magical potions.

Joannie was officially diagnosed with Philadelphia Positive Chronic Myelogenous Leukemia - CML. She was told she had 2 - 4 years to live and was too old for a bone marrow transplant. She had no siblings for a possible bone marrow match anyway. So now "The Beast" was discovered, awake and roaring. Their lives had changed forever.

Jerry, stayed by her side every day then each night at home, he researched leukemia, anatomy and physiology of blood, WBC, RBC, platelets, and everything in between. He searched for cures, treatments, prognosis, experts of all sorts, trials, any word of hope for our future together. The information he found in 2001, was not very encouraging and confirmed a short life expectancy. There was no cure. What a blow!

After 2  $\frac{1}{2}$  very painful and interesting days her extreme white blood count had been reduced to only 4 times normal. Life was becoming better by the hour. Her physician surprised her by saying, "If you have to have a cancer, this is the one to have." What? A new oncologist/hematologist then introduced her to a new drug, the first of its kind. It had just been approved by FDA 3 months before and accepted on the insurance formulary less than 2 weeks before. This miracle targeted drug might extend Joannie's life. Her new prognosis - Unknown. This drug had such a short history, but it looked promising.

OMG ... she felt she was the lucky one!!! Imagine that! A drug that might extend her life beyond 4 years! Not a cure but hope rushed in and lifted our spirits! Now, would this new drug work on her and if so, for how long? No matter how long it took or how difficult the journey, she decided that she would fight The Beast! He wanted to take Joannie's life, but she was a formidable opponent, and The Beast would have to fight her for it with the help of her new weapon - imatinib mesylate.



There was so much information to process in just a short amount of time. There were so many heightened emotions with which to deal. Continuous communication, with friends and family members all over the U.S. and Europe, status and updates were important and time consuming. What about a second opinion? What about the future? What about the garage she had to clean out! She had so many questions yet to be answered.

Placed on a drug that was designed to control her specific rare kind of Leukemia - CML. She kept in mind that this drug had only been developed 2 years earlier. Neither longevity nor long term efficacy was yet known. In trials, it had been proven to be about 80% effective in controlling CML with fewer and more manageable side effects than alternative chemotherapy. She and Jerry would have to see about that. Today there are at least 5 other oral treatment options available.

Because this innovative drug was her only option, she plowed through each side effect one challenge at a time. For the first 4 years, she would experience 6-8 side effects concurrently and allergic reactions to the drug. After several years her body accepted this lifegiving infiltrator. Today only 3-4 side effects remain. This was her new normal life.



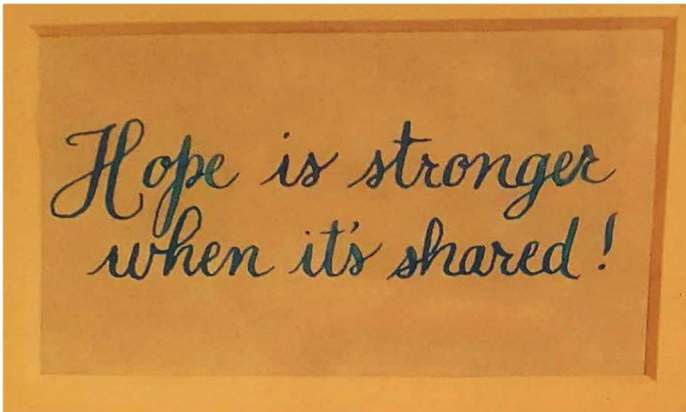
Since then and every day for the rest of her life, she takes her required dose of medication called a TKI. It saves her life and challenges her still. Daily, Joannie manages side effects and juggles her dosage. Regular blood tests and visits to her health care team of doctors is required for monitoring CML. Her PCR results still fluctuate but remain low and even though she is comfortable with these results she would love to be undetectable and

eligible for treatment discontinuation (TFR).

With those small inconveniences, she receives the blessing of LIFE itself. How could she not pay-it forward? But what about all those unanswered questions? Surely, other newly diagnosed patients had questions about this rare cancer and this new CML treatment?

On November 8, 2003, a dear CML friend and Joannie co-founded what would become "CML Busters" a CML specific Family Support Group, with the support of outside organizations. Their





Meet and Greet with Researchers

first meeting brought 16 confused, scared, "CMLers" and their family members. It was discovered each one had similar stories, many questions and all were taking the same targeted medication. We traveled around the table each sharing a story of a journey to diagnosis and the unique challenges each was experiencing. This model of peer-to-peer sharing proved to be the cement which holds this group together to this day. As it turned out these newly diagnosed patients were part of the "first generation guinea pigs" after the drug trials. Several of the "CMLers" took part in the risky drug trials held 2-3 years earlier. Each one of these CML warriors is a TKI pioneer and hero.



Friends for Life

For over 19 years, each month, CML Busters FSG meets face to face and virtually, with newly diagnosed CML patients and long-standing members still in need of hints for living better with CML or just in need of a hug. The knowledgeable and experienced members hear each new story, share challenges or transitions, discuss, and offer personal CML experiences.

Each newly diagnosed person arrives in fear and uncertainty and leaves our meeting empowered to LIVE their new life with hope, better equipped to manage their disease and feel they are in better control of their lives again! CML Buster Support Groups have grown to over 400 patients and their families. Every month each warrior has their opportunity to pay it forward to the next generation of CML warriors. ***Their goal is to satisfy the important mission of empowering, educating, advocating, comforting, offering an understanding heart, and give hope.***

Joannie has recently celebrated her 20<sup>th</sup> year after diagnosis! She wishes she could say she was "cured" but "The Beast" still dwells within and raises its ugly head to remind her of its threatening presence. Thank goodness for innovative new treatments because...

***Instead of Roaring, for now, The Beast is just Snoring.***

