LEUKEMIA & LYMPHOMA SOCIETY®
fighting blood cancers

MPN Connect

Use this resource to read about and connect with other patients and to learn about The Leukemia & Lymphoma Society's (LLS) online social network and registry, **LLS Community**, the one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff.

PATIENT STORIES

My name is Ron and fortunately for me, my blood cancer journey has been a long one. I currently have myelofibrosis (MF), a type of myeloproliferative neoplasm (MPN), and this is my 32nd year of it being a part of my life.

I have secondary myelofibrosis. I was originally diagnosed with an essential thrombocythemia (ET)/polycythemia vera (PV) blend. It then evolved into PV and then into MF in the last 7-8 years.

I have seen MPN knowledge and treatments evolve from the rather archaic times of the 1980's when only a portion of information could be found in a medical journal in the library, to now having many medical centers around the world involved with multiple ongoing studies, research, thousands of professional papers, and many treatment strategies within the MPN umbrella of cancers.

The approach I took on my medical journey (and it likely applies to many patients) is a quote by Albert Einstein. He said, "Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning." Learn, Live, Hope – three good words for any blood cancer patient.

So the "Learn, Live, Hope" philosophy is at the center of how I live my life with an MPN. I have gone from the typical raw and dreadful feelings of hearing those first words "you have cancer," to learning, living and hoping for even better outcomes tomorrow. Attitude is important, since a person that gives in to the absolute fear of cancer will be hard pressed to accept it, but not concede to it. Respecting cancer is key, but I do not concede to it without challenging it at every level (expert doctors, treatment/prescription drugs, and mind and body awareness). So in the case of having an MPN and it being a chronic cancer without a cure, it is important to realize that it will be a part of your life. It does not have to run your life, rather you must live your life with cancer as a part of it.

For new patients, The Leukemia & Lymphoma Society (LLS) is a great resource to get credible and useful information on their specific blood cancer diagnosis, as well as to learn more about support groups, financial assistance, education information and other resources. Virtually every newly diagnosed MPN patient today, as well as myself back in the 1980's, had never heard of MPNs, let alone knowing what MPNs are all about. LLS helps patients figure all that out. Even after surviving for 32 years and attending MPN conferences around the country to keep up on the progress in MPN research, I still turn to LLS to keep up with the latest information.

I can happily say that I have now lived longer with blood cancer in my life (over 32 years!) than I have lived without cancer (31 years). Has it been a walk in the park? Not at all, as there have been some hills and valleys along the way. But with the amazing progress being made in MPN treatments, knowledge, and understanding, I am able to walk in the park and continue to enjoy life all around me!

Cynthia

I was diagnosed in December of 2015 with polcythemia vera (PV). I also had type 2 diabetes and my calcium levels were high. I knew something was wrong when I would take a shower and my skin would begin to itch so badly. I went to the best dermatologist who told me to stop using products with fragrances. I tried that and it did not work and the itching continued. My doctor referred me to one of her friends who was an oncologist. The oncologist ordered a bone marrow biopsy and discovered PV. Now, I am doing wonderfully and the itching stopped after taking hydroxyurea. ■

Randy

I was diagnosed with non-Hodgkin t-cell lymphoma (1st blood cancer diagnosis) in October of 2008. The blood cancer was already in the bones of my body...stage 4. My wife asked me if I was scared. I thought to myself and then answered her, “I can’t change my body and I can’t change my blood, so I will just pray and keep on living.” I received four sessions of CHOP (cyclophosphamide, doxorubicin (hydroxydaunorubicin), vincristine (Oncovin ®), prednisone) chemotherapy and was in remission after exactly one year. However I was then diagnosed with pre-b cell acute lymphoblastic leukemia (2nd blood cancer diagnosis) and had to be admitted to the hospital for more chemotherapy, I received 12 sessions of full-body radiation, and a stem cell transplant. With prayers and trust in God, my sister and brother were both perfect matches for a stem cell transplant. The bad news however, was that I was now diagnosed with a 3rd blood cancer called myeloproliferative neoplasm (MPN). In the hospital for treatment, each passing day was full of prayers, hope, and strengthened faith. Never give up because “when there is life there is hope.” On the 16th of March 2010, I was in complete remission of all three of my blood cancer diagnoses; lymphoma, leukemia, and MPN. I am the first documented case to survive!!! I attribute my healing to God my father, a hopeful attitude, and a fighting spirit that you wouldn’t believe. ■

LLS has an online social network and registry for patients with and survivors of blood cancer, their caregivers and their supporters called **LLS Community**.

Why Should You Join LLS Community?

Members of the LLS Community benefit from connecting with other patients and caregivers and by sharing their experiences which inform research and program development at LLS.

Get Support from LLS Community

Connect with others who have been through it. LLS Community is a place to talk with other people affected by blood cancers. We also have master's level social workers and health educators standing by to connect you to the resources you need.

Get Information from LLS Community

Get access to the latest cancer news and updates. On LLS Community, you will find professional blogs, summaries of medical publications and videos featuring top experts from cancer centers around the world.

The information on LLS Community is accurate, up to date and from a trusted source.

Patients and Caregivers Can Make an Impact

Too often, traditional research has excluded the patient voice, the voice that matters most. LLS Community features Questions of the Day and surveys designed to capture important patient-related topics.

These insights are actively driving the developments at LLS that address the needs and challenges of patients living with blood cancer.

To join, visit **www.LLS.org/community**.

5,954	**Community users** (total)
16,434	**Community comments**
151	**Members on MPN Board**
49,448	**Question answers**
52	**Average user's age**
50	**Average age at diagnosis**
3,954	**Diagnosed members**
1,163	**Caregiver members**
1,172	**Supporter members**

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*Numbers as of September 2017

GET SUPPORT.
REACH OUT TO OUR INFORMATION SPECIALISTS

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

Contact us at **800.955.4572** or **www.LLS.org/InformationSpecialists**