## AN INSIDER'S POINT OF VIEW

## **Turning Adversity to Self-Advocacy**



Mary Cotter, CR&T Patient Committee Member

he 12th International Patient Symposium on Myeloproliferative Neoplasms (MPNs) is a conference presented by the Cancer Research & Treatment Fund (CR&T) and is designed for MPN patients and families to help them learn about these diseases. Myeloproliferative neoplasms [MY-ah-lo-pro-LIF-er-uh-tiv NEE-o-plaz-uhms] are a group of chronic blood cancers and at this conference, patients have direct access to leading MPN researchers and physicians from around the globe providing a truly unique experience, connecting patients with doctors leading the forefront of treatment and research for their disease.

CR&T's MPN Patient Symposium, first organized by Dr. Richard Silver, is hosted in Manhattan, and I first attended the Symposium in November of 2011 at the urging of my fellow MPN patients. I was newly diagnosed and discovered a lack of knowledge and resources in my community. New York City is not

far from my home in Connecticut, although people travel from all over the country, and even internationally, to attend this conference. I have not missed a Symposium ever since. In fact, in 2018 Dr. Silver asked me to join the CR&T Patient Committee which advises and assists with planning the Symposium agenda to reflect the issues that patients want to know.

At my first MPN Symposium, I initially felt overwhelmed by the science and research presented, but I wanted to know as much as I could about my disease, so I listened. I learned that the presenters were accessible and wanted patients just like me to know there were treatments and importantly - hope. Having a diagnosis of cancer is a frightening experience, and even more so when it is a cancer most people have never heard of. By attending the Symposium, I quickly learned that I need not be frightened. I became a knowledgeable self-advocate, because the expert MPN doctors at the Symposium trusted me, the patient, with the same information they were sharing with their colleagues. This empowered me to find a local team of hematologists who would trust me and work with me to create a treatment plan that is right for me.

I encourage my fellow MPN patients to come to the MPN Symposium and bring a family member or friend with you. When I received my MPN diagnosis in March of 2011, I felt so alone. I did not know anyone with this disease. By attending the MPN Symposium, you will meet other MPN patients and develop lasting relationships. When you return home, you will know you are not alone on this journey.

All of the information about CR&T's 12th International Patient Symposium on Myeloproliferative Neoplasms (MPNs) is available on the Cancer Research & Treatment Fund website (www.crt.org) and you can always give Chad a call at the CR&T office (212-288-6604), send him an email (cfeay@crt.org), or use the registration form on page 6 of this issue.

It has been a few years since the MPN Patient Symposium was held, so I am looking forward to seeing Dr. Silver again, and having live, not Zoom or Facebook, conversations with my fellow patients, many of whom have become real friends. I hope to meet you too at the 12th International Patient Symposium on Myeloproliferative Neoplasms.

Mary Cotter is a Certified Career Counselor and Certified Rehabilitation Counselor/Vocational Evaluator and has been in practice for 33 years. She has attended CR&T events since her MPN diagnosis in 2011. Mary resides in Mystic, CT with her husband Brian. Mary competes in canine agility competitions with her golden retrievers, Jag and Trig.



Mary Cotter, far right, and others listening to Dr. Hans Hasselbalch at CR&T's 10th International Patient Symposium on MPNs