

The 5th International MPD Patient Symposium by David Boule



Let's start with the basics--What is a myeloproliferative disease (MPD)?

There are four myeloproliferative diseases which share many clinical characteristics and reflect over activity of the bone marrow. These are polycythemia vera (PV), essential thrombocythemia (ET), primary myelofibrosis (PMF), and chronic myeloid leukemia (CML). CML is split off from the other three because it is characterized by a specific chromosomal abnormality and very specific drug treatment which results in prolonged remission and possibly cure.

The other three clinically related myeloproliferative diseases (MPDs) will be discussed at the Patient Symposium. In these MPDs, the marrow cells that produce blood cells function abnormally and overproduce (proliferate) red blood cells, white blood cells and/or platelets. PV and ET are chronic diseases which generally can be managed over the long term with appropriate treatment. PMF is chronic and develops without any antecedent disorder. Sometimes, a clinically similar picture develops in late stages of PV and ET.

Currently, there is no known cure for any of the MPDs. But significant advances in understanding the MPDs have been made recently with the discovery of a mutated gene (JAK2 V617F) found to be highly associated with the MPDs, especially PV. (Researchers at Cornell have found the JAK gene to be present in virtually all patients with PV). Additionally, alternative treatments have been developed, particularly using low doses of interferon which can reduce or even stop fibrosis of the bone marrow associated with advancement of the diseases. Moreover, there are several clinical trials currently being conducted as a result of the discovery of the JAK2 gene mutation.

The 5th International MPD Patient Symposium

Dr. Richard T. Silver, Vice President and Medical Director of CR&T, has long been recognized worldwide as a leading expert in the diagnosis, treatment and clinical research related to MPDs. Under Dr. Silver's leadership, the CR&T sponsored its first MPD Patient Symposium in 2001. The Patient Symposium immediately preceded the inaugural International Congress on Myeloproliferative Diseases and Myelodysplastic Syndromes for physicians which Dr. Silver also initiated.

Dr. Silver recognized the need to provide a forum for MPD patients to come together to learn from both the physicians and clinical researchers who specialize in their

disease because these diseases are not widespread (the best estimate is that fewer than 200,000 in the US have one of these three MPDs). As importantly, Dr. Silver recognized the need for the patients to have the opportunity to talk with others about how they cope with their disease.

In 2007, Dr. Silver asked the MPD Foundation, a Chicago based organization to co-sponsor the event and to invite the many MPD patients on its list to attend the symposium in New York City. Like CR&T, the MPD Foundation raises funds and distributes grants to researchers engaged in finding a cure or better treatments for MPDs. In 2009, the MPD Foundation will also co-sponsor the Symposium. This approach allows the Symposium to keep patient ticket prices low and allow access to the broadest possible MPD patient audience.

We expect to have more than 200 patients attend the Symposium on November 4, 2009 at the New York Athletic Club. We're really looking forward to a great MPD patient educational experience. More informed MPD patients can be more effectively involved in their own treatment.

Dr. Silver asked me, as a member of both the CR&T and MPD Foundation Boards and a PV patient, to lead the planning for the Symposium event. I was honored and pleased to accept the chairmanship of an inaugural "MPD Patient Committee" to provide input to the Symposium Agenda that Dr. Silver is constructing in his role as Symposium Chair. I hope, with the assistance of a patient committee, to help produce a very interesting and productive educational program for all who attend this symposium. The Patient Committee includes patients who have PV, ET and PMF. We will meet in April to discuss ways the patient experience at the Symposium can be enhanced. Dr. Silver said "We want to provide the patients with the most valuable and useful day possible". I am also working closely with Mike Wargo, CR&T Vice President of Development and folks from the MPD Foundation to plan and execute the Symposium.

Since its formation in 1968, CR&T has been dedicated to exploring blood cancers as the gateway for the cure for many other cancers. CR&T has focused on finding the most effective ways to bring the lab closer to the patient's bedside in the ongoing search for a cure for cancer. The MPD Patient Symposium, where over 200 patients will get to interact with leading MPD clinicians and physicians from the world's leading institutions, is an important aspect of CR&T's dedication and focus.