Suggestions for the newly diagnosed

Find an expert
Finding an expert in myeloproliferative disorders is the first and most important step you can take. Because MPDs are rare and their side-effects can be life threatening, only a knowledgeable hematologist/oncologist should treat patients. If you are in a remote location, ask your doctor to consult with a leading MPD doctor.

Educate yourself
Understand all that you can about your disorder to help you recognize danger signs and keep abreast of new treatments.

Eat well and stay active
Good general nutrition and, with a doctor's approval, moderate exercise will help you stay healthy.

Communicate
Talk to your doctor, family and friends for support or join a local or online group to help you feel empowered. For more information, visit our web site:
http://www.scn.org/CBCs-R-Us/

Have regular blood tests
See your doctor as needed and keep to his/her schedule of recommended blood tests.

Have your blood counts checked at your regular yearly physical. 70% of patients with MPDs reported that they never experienced symptoms prior to diagnosis. Ask your physician for copies of your blood report and question any result outside the normal range.

Visit our Seattle Area Support Group at:
http://www.scn.org/CBCs-R-Us/

This brochure was created by the Seattle CBCs-R-US MPD support group and is not meant to replace the advice of a medical doctor. It was developed to help MPD patients and their friends and families to understand the basic elements of their disorder. It is not a substitute for sound medical advice and does not advocate any specific treatment methodologies. Space does not allow us to cite all the sources used for this brochure.

MPDs

MYELOPROLIFERATIVE DISORDERS

Get your complete blood count (CBC) every year!

A brief guide to understanding

Polycythemia Vera (PV)
Essential Thrombocythemia (ET)
Agnogenic Myeloid Metaplasia (AMM)
Idiopathic Myelofibrosis (IMF)
Chronic Myelogenous Leukemia (CML)

Myeloproliferative Disorders or MPDs are a group of rare hematological disorders. There are several individual diseases that are categorized as MPDs, including:
- Polycythemia Vera (PV)
- Essential Thrombocythemia (ET)
- Agnogenic Myeloid Metaplasia (AMM)
- Idiopathic Myelofibrosis (IMF)
- Chronic Myelogenous Leukemia (CML)

A Brief Description of MPDs
In a normally functioning body, blood cells are formed in the bone marrow. With an MPD, the bone marrow overproduces the normal amount of blood cells, resulting in a variety of problems. Cells may behave normally, some may be immature, and others may lose their ability to function properly.

In each type of MPD different cells are affected. In **ET**, it is the platelets, the cells responsible for the blood's ability to clot, that are overproduced. There are many factors that indicate whether a person has ET but an increase in platelets above 400,000 is the first step toward a diagnosis.

In **PV**, the red cells show the most marked increase, although platelets are also commonly elevated in PV. White cells may be elevated, as well.

In **CML**, the white blood cells increase to a dangerous level.

For simplicity's sake, in this brochure, **myelofibrosis** is broken down into two categories: **AMM** and **IMF**. Treatment and life expectancy vary greatly between these two diseases.

Agnogenic Myeloid Metaplasia (AMM) is used to describe myelofibrosis that can develop after many years of living with ET or PV. Current theories suggest that AMM may be a natural progression for ET and PV.

Idiopathic Myelofibrosis (IMF) is used to describe myelofibrosis as the primary diagnosis, in the absence of ET or PV.

Symptoms
An MPD may appear suddenly with or without any major symptoms. At first, many patients are asymptomatic, meaning they have no or very mild symptoms when diagnosed. Some patients are extremely symptomatic and suffer from headaches, dizziness, visual disturbances, numbness in their extremities, or a number of other symptoms. Others experience serious complications, including stroke, aneurysm or deep vein thrombosis. In most cases, proper treatment will eliminate these troublesome symptoms and help reduce the risk of life-threatening complications.

Diagnosis
A Complete Blood Count or **CBC** is a simple blood test that is the first step in diagnosing an MPD. The blood test will indicate if any of your individual blood cell types are elevated. Elevated blood counts can be a result of many different medical problems, including simple infections, and elevation of cells alone is not a definitive test. A bone marrow biopsy is also typically needed to confirm the existence and type of MPD. In CML the Philadelphia Chromosome is affected in 90% of patients and a chromosome study is needed to confirm this diagnosis. An increase in spleen size is also common in these diseases. Most cases of MPDs are found in people over the age of 50, although there are reported cases of children, and today more young adults in their 20s and 30s are being diagnosed.

Treatments
There are many treatment options for people with myeloproliferative disorders, depending on your specific disease, age and condition. The most common treatments are one or a combination of the following medications: Aspirin, Anagrelide Hydrochloride (Agrylin), Hydroxyurea (Hydrea), and Interferon. PV patients also depend on phlebotomies to decrease red cells. These treatments do have side effects and most patients manage them very well. Patients with advanced Idiopathic Myelofibrosis and CML typically require more aggressive treatment, depending on their condition.

Disease Progression
Disease progression is currently being studied. Most PV and ET patients do extremely well with treatment and live healthy lives with normal life expectancy. Some experts suggest that myelofibrosis (AMM) is a natural progression of these diseases. A small percentage of PV and ET patients develop leukemia. This is a rare occurrence. Life expectancy for patients with CML and idiopathic myelofibrosis vary depending on patient age and disease progression.

Support
While MPDs are relatively rare, there are concentrations of patients in large metropolitan areas who have created local support groups. For support, visit **http://www.scn.org/CBCs-R-Us/**