

MPD FOUNDATION UPDATE

A PERIODIC NEWSLETTER FOR
THE MYELOPROLIFERATIVE DISORDERS COMMUNITY

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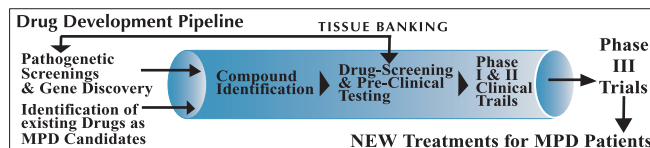
MPD RESEARCH ALLIANCE: HEADING FOR NEW TREATMENTS

For the first time ever, leading MPD researchers from three important institutions have joined forces to accelerate the development of new treatments. It could not have happened without us.

On April 1, 2006, the MPD Foundation awarded \$800,000 to fund the first year of the MPD Research Alliance. The lead investigators are Gary Gilliland, PhD, MD, Harvard Medical School; Ronald Hoffman, PhD, University of Illinois at Chicago; and Ayalew Tefferi, MD, Mayo Clinic, Rochester.

An Ambitious Goal: Extending Our Lives

The primary goal of the MPD Research Alliance is to accelerate the development of new targeted therapies that will materially benefit MPD patients. These treatments will address all the Philadelphia chromosome negative myeloproliferative disorders (Essential Thrombocythemia, Polycythemia Vera and Myelofibrosis) and include patients with and without the JAK2 mutation. (In 2005, researchers made a major breakthrough by discovering a genetic mutation – technically known as JAK2 V617F – that occurs in most PV patients and many ET and MF patients.)



Research Alliance Priorities

Identify the best candidates for development among compounds available today for JAK2 positive patients, and quickly move them through the drug development pipeline and into clinical trials for JAK2 positive patients.

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LETTER FROM THE PRESIDENT

By Robert Rosen

When my doctor told me that I had PV in late 1997, two questions quickly came to mind – I asked whether anyone was doing medical research in this area, and if there were any advocacy groups representing the interests of MPD patients. His answers left me feeling even more alone with my diagnosis, but they also planted the idea for creating a new advocacy group. Toward the end of 1999, three other patients and I started the MPD Foundation. Now, six years later, there is much to report.

Happily, in early 2006, two new major research initiatives are being launched that will specifically target our patient group. The MPD Foundation is sponsoring and funding one of these initiatives, and has had a hand in promoting and providing seed money for the other.

Launch of Two Significant Research Initiatives

This month, the MPD Foundation is formally announcing the launch of the MPD Research

Alliance, which is discussed in detail in our front page article. For the first time, there is a major MPD research effort focused on drug discovery.

Additionally, the National Cancer Institute has awarded the MPD Research Consortium a \$26.5 million grant to conduct a wide range of studies for MPD patients in the context of an international collaboration between noted MPD research scientists and physicians. The MPD Foundation was proud to award the Research Consortium two timely organizational grants that made it possible for this group to pursue the lengthy application process to the National Cancer Institute.

\$26.5 Million National Cancer Institute Grant Jump Starts the MPD Research Consortium

These new initiatives, coming on the heels of the stunning discovery last year of the role of the JAK2 genetic mutation in many MPD patients, has ushered in a new age of MPD research. We are proud to be part of it. We can truly begin to visualize an era where patients can benefit from improved treatments or perhaps a cure, and where our doctors will have more tools to understand which treatment options will work best for individual patients.

Stay tuned during these exciting times. We will post periodic updates on our website as these projects move forward. Special thanks to all our supporters for making this work possible.

MPD RESEARCH ALLIANCE CAPITAL CAMPAIGN

A Great Opportunity to Make a Difference

In the Fall of 2005, the MPD Foundation launched a capital campaign to raise \$10 million over five years to fund the MPD Research Alliance.

Thanks to the generous lead gift of \$500,000 from Robert Pritzker, chair of the campaign, the MPD Foundation was able to initiate the Research Alliance. To date, \$1,000,000 has successfully been raised to begin this unprecedented approach to MPD research.

Funding the MPD Research Alliance is a major undertaking for the MPD Foundation. It is imperative that we continue the momentum in MPD research, a goal that requires an unwavering commitment from our supporters.

There are many ways to give to the MPD Foundation, and we appreciate gifts of any size. Gifts of cash, including checks and credit card donations are always an option. Many donors choose to make pledges that extend over a number of years, enabling the Foundation to develop long-range financial plans based on predictable income. A number of Planned Gift opportunities are available and offer substantial tax advantages.

Help us pave the way to future hope and promise for MPD patients. Provide the critical financial boost needed to sustain the MPD researchers on their quest for new drugs and a possible cure.

Please contact Ann Brazeau, Associate Director, at 312-683-7226, with any questions you may have about contributing to the MPD Research Alliance Capital Campaign.

MPD RESEARCH ALLIANCE: HEADING FOR NEW TREATMENTS

(continued from page 1)

Identify and validate new targets in MPDs that are JAK2 negative and develop new compounds that are effective against these targets.

Initiate Phase I and Phase II clinical trials to provide a better understanding of which compounds work best in which patients.

We plan to work with biotechnology and pharmaceutical companies to carry the most promising compounds through the large and expensive Phase III trials required for FDA approval.

Highly Qualified Independent Advisory Board

In support of the MPD Research Alliance, the MPD Foundation has recruited an impressive Scientific Advisory Board to provide an independent assessment of research progress against objectives, and to make recommendations where improvements or changes may be needed.

Members of the Advisory Board are Ernest Beutler, MD (Chair), Scripps Research Institute; Martin Tallman, MD, Northwestern University; Josef Prechal, MD, Baylor College of Medicine; Hugh Rosen, PhD, MD, Scripps Research Institute; and Connie Eaves, PhD, BC Cancer Research Center.

A Different – and Better – Approach to MPD Research

The MPD Research Alliance is a novel approach to MPD medical research because of the unusual collaboration of researchers at three different institutions. Also, many traditional research models are aimed at advancing the science without a specific focus on improved treatments.

Key to this effort is that patients are involved in the process. In addition to raising money, widespread patient involvement provides researchers with easy access to a broad range of tissue samples and volunteers for clinical trials.

“The traditional model of medical research has not been yielding progress nearly fast enough,” says Robert Rosen, President of the MPD Foundation and an MPD patient. “The existing treatments for MPDs were originally developed to treat other diseases, and they all can have severe side effects. Our goal is to make new targeted treatments available that will help current patients as well as future generations.”

MPD FOUNDATION SPONSORS NEW EPIDEMIOLOGY STUDY

Demanding a Recount: MPDs May Not Be as Rare as the Experts Think

If you or someone you know has an MPD, you’ve probably been told it’s a rare or “orphan” disease, with one or two cases per 100,000 people. That has been the common wisdom for decades – and it may be way off the mark.

Preliminary analysis of insurance data suggests a much higher prevalence than the current literature reports. This is of great significance to the MPD community, pharmaceutical companies and research agencies; we believe that establishing a more accurate view of MPD prevalence and incidence will have a profound impact on public policy and stimulate research into new treatments.

How Many of Us Are There?

The MPD Foundation is sponsoring an epidemiologic study of the Chronic Myeloproliferative Disorders. Epidemiology is the study of the distribution and determinants of disease in a population. The Leukemia and Lymphoma Society is co-funding the study.

Together we have awarded a one-year grant to Xiaomei Ma, Ph.D., Assistant Professor in the Department of Epidemiology and Public Health at Yale University School of Medicine.

The specific aim of the study is to evaluate the incidence and prevalence of the myeloproliferative disorders in the United States. The study will also analyze the data for potential gender and age differences in the prevalence and incidence of MPDs.

*For Progress Reports
please see our website at
www.mpdfoundation.org*

PLANNED GIVING A LIFETIME OF SUPPORT

Planned gifts are wonderful ways to benefit the MPD Foundation and help ensure its future viability.

Through careful planning, you may find you can give more than expected and also provide a lifetime of income for yourself or loved ones.

A *will* is the simplest and most common form of planned giving. Donors can protect their dependents, reduce their estate taxes, and control the way in which their assets are distributed and to whom.

Charitable Gift Annuities are an easy way to make a charitable gift and receive an annual income. You can fund a gift and receive an annual income.

Charitable Remainder Trusts make periodic payments to one or more individuals for life or for a term of years. There are two types of charitable remainder trusts:

Unitrust: income fluctuates annually as a fixed percentage of the fair market value of the trust. This type is best for those who want to participate in market gains and can tolerate some risk. *Annuity trust*: income payments are fixed and determined when the gift is made. This is attractive to individuals who wish to avoid risk.

Gifts of Life Insurance. If you have a life insurance policy that you no longer need, a gift of a life insurance policy can be a way to combine charitable objectives with tax advantages for you.

Gifts of Personal Property. Mutual funds, corporate stock, and government, corporate and municipal bonds are the most common types of personal property gifts. They are easy to value and are simple to transfer. Tangible items such as, paintings, photographic exhibits, sculptures, stamp and coin collections, are also treasured.

Retirement Benefits. If you are planning to divide your estate between the MPD Foundation and your heirs, there can be significant tax advantages – both income and estate – to naming the MPD Foundation as beneficiary of your IRA, 401(k) or other qualified retirement plans, and leaving your other assets to your heirs.

Planned gifts should be designed with care. You and your advisor can determine what is most appropriate and beneficial for you.

For more information about the MPD Foundation's Planned Giving Program, please contact Ann Brazeau, Associate Director, at 312-683-7226, or visit our website at mpdfoundation.org.

For more information or to make a donation, contact the MPD Foundation at:

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