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MPD Research Consortium members and others gather at the home of Robert and Ellen Rosen: (from left to right) Heike Pahl, Roberto Marchioli, Josef Prchal, Atilio Orazi, Kim Cosino, Ron Hoffman, Carol Ferrans, Robert Pritzker, Anna Rita Migliaccio, Tiziano Barbui, Gianni Barosi, Damiano Rondelli, and Robert Rosen.

## MPD RESEARCH CONSORTIUM CONTINUES TO PURSUE NCI GRANT

### MPD Foundation Funding Helps Get the Effort Started

The Myeloproliferative Disorders Research Consortium, originally organized by Dr. Ron Hoffman at the University of Illinois at Chicago Cancer Center, represents a collaboration of 21 researchers and clinicians at 14 institutions worldwide.

*The Consortium has a number of goals:*

- International collaboration to facilitate basic and clinical research dealing with the cellular and genetic basis of PV, MF and ET
- Evaluation of biomarkers that correlate with known clinical parameters, and identification of novel therapeutic agents for treatment
- Establishment of a shared multi-institutional tissue bank
- Development of a secure interactive Web site that will enable all consortium members to maintain and share a common database

*(Continued on page 2)*

## HOW ARE WE SPENDING YOUR MONEY?

### Over \$2.5 Million in Research Grants to Date

The Board of Directors has announced three new research grants and voted to continue funding for the MPD Research Consortium. Details of the new research projects will be discussed in the Fall issue of Update.

*Since 2000, the MPD Foundation has funded the following research projects:*

#### 2000

Josef Prchal, MD  
Baylor College of Medicine  
PV Gene

#### 2001

Josef Prchal, MD  
Baylor College of Medicine  
ET Gene (funded by Friends of ET)  
Josef Prchal, MD, Baylor, continuation of  
PV Grant

#### 2002

Vahid Afshar-Kharghan, MD  
Baylor College of Medicine  
PV/ET and platelets (co-funded with LLS)  
Josef Prchal, MD, Baylor, continuation of  
PV Grant  
Josef Prchal, MD, Baylor, continuation of  
ET Grant by Friends of ET

#### 2003

Xiao-Feng Yang, MD, PhD  
Baylor College of Medicine  
Novel Antigens for Immunotherapy in MPDs  
(co-funded with LLS and Friends of ET)

Ruben Mesa, MD  
Mayo Clinic  
Myelofibrosis with myeloid metaplasia (co-funded with Friends of ET)

Ron Hoffman, MD  
University of Illinois at Chicago  
Organizational grant for MPD Research Consortium

Richard D'Andrea, MD  
Child Health Research Institute, Australia  
PV Growth Factor receptor mutation (funded by LLS)

Vahid Afshar-Kharghan, MD, Baylor,  
continuation of Grant with LLS and Friends of ET

#### 2004

Mingjiang Xu, MD, PhD  
University of Illinois at Chicago  
Role of PTP-MEG2 in PV

Alison Moliterno, MD  
Johns Hopkins University  
Proteomic approach to MPD's

Jose Lopez, MD  
Baylor College of Medicine  
Thrombosis in MPD's (funded by LLS)

Afshar-Kharghan, continuation of Grant with LLS and Friends of ET

Xiao-Feng Yang, MD, PhD, Baylor,  
continuation of Grant with LLS and Friends of ET

Ruben Mesa, MD, Mayo, continuation of Grant with Friends of ET

Richard D'Andrea, Child Health Research Institute, continuation of Grant by LLS

Ron Hoffman, MD, UIC, renewal of Grant for MPD Research Consortium

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## NCI GRANT *(Continued from page 1)*

The MPD Foundation provided a \$25,000 startup grant to fund the consortium's first project: the preparation of an 800-page program project application to the National Cancer Institute for a five year grant.

Disappointingly, the first-time program project application was not approved. But initial rejections are not at all unusual. Often, program project applications are funded only after three review cycles. Based on recommendations from NCI reviewers, the MPD Research Consortium submitted an amended

proposal in June, 2004, and is hoping for a favorable response.

Dr. Ron Hoffman, director of the MPD Research Consortium, is also a member of the Medical Advisory Board of the MPD Foundation. Dr. Hoffman said that "MPD Foundation advocacy for the MPD Research Consortium program project reinforced the urgency and need for a major nationwide research program to find better ways to prevent and reduce the effects of these diseases."

## ET Patient and MPD Foundation Supporter Takes Us to the Races

by Gregg Teel

In July 2003, I had a painful flare up with my back and decided to go in for my third lower back surgery. During the pre op blood work, my platelets were at 1.4 million, and red and white counts were also slightly high.

My general practitioner contacted Dr. Kathryn Arrambide, a hematologist/oncologist who had recently moved to our town – Quincy, Illinois – to join the new Cancer Center at Blessing Hospital. Dr. Arrambide diagnosed me with ET, which meant absolutely nothing to my wife Lori and me. Lori found a lot of scary information on the Internet, but Dr. Arrambide suggested a few sites that she trusted to have more reliable information. [Good for her! – Ed.]

Then I ran across the MPD Foundation site. It gave me a lot of useful information and links to other sites. I thought I might be able to do something in return, so I contacted Robert Rosen at the MPD Foundation and we discussed adding the Web address on our race car in hopes of bringing more awareness to the general public. We also have fact sheets and newsletters available at the races.



Gregg Teel's 1967 Camaro SS taking off.

Did I say race car? You bet I did.

When I was a small child my father raced cars. He still does, and so do my brother, my brother in-law and his father. We also enjoy muscle cars, car cruises and most anything that goes fast. I have been lucky to have a wife who is supportive of taking all of our spare change and throwing it into car related items.



Paige Teel, age 2, looking out at the world from the window of our 1967 Camaro SS.

Our race car is a 1967 Camaro SS that I race in the Super Stock classes at NHRA (National Hot Rod Association) and IHRA (International Hot Rod Association) events in the Midwest. I have been trying to get into the nine second range for a couple of years, and I recently ran my best elapsed time in the quarter mile – 9.97 seconds at 130 mph. No way am I going to let ET slow me down.

Incidentally, I've been taking Agrylin to control my platelets, and when they got back to the 500,000 range my back started to feel better. I cancelled my back surgery and through physical therapy have returned to a lifestyle pretty similar to what I had before my diagnosis.

## RESEARCH UPDATES

### Searching for Potential New Therapies

The MPD Foundation awarded a grant to Dr. Ruben Mesa, Dr. Ayelew Tefferi and their colleagues at the Mayo Clinic Rochester.

The Mayo team is exploring potential new therapies for advanced myeloproliferative disorders, and has to date evaluated CC-5013 (Revimid), Arsenic Trioxide, Seocalcitol, Bortezomib (PS-341), Adaphostin, R115777 (tipifarnib), CCI-779, and inhibitors of VEGF (vascular endothelial growth factor).

Preliminary results suggesting potential benefits with some of these agents have led to new clinical trials for myelofibrosis and related diseases with Revimid, Arsenic Trioxide (with ascorbic acid), and PS-341 (in conjunction with MD Anderson Cancer Center.)

Many additional agents are in the investigative pipeline; the Mayo team's goal is to find practical and applicable therapies in the near future.

Additionally they are using the new technology of proteomics to compare the differences in proteins and genes in the blood stem cells of MPD patients and controls. Collaborating with the state of the art proteomics center at Mayo, they are working to expand the data and interpret the importance of the differences between patients and controls.

### The Search for MPD Antigens

Last year the MPD Foundation and the Leukemia & Lymphoma Society jointly funded a research project headed by Dr. Xiao-Feng Yang of Baylor University. Dr. Yang's team is collaborating with Dr. Josef Prchal, the recipient of the first MPD Foundation grant in 2002 and now a member of our Medical Advisory Board.

Here is Dr. Yang's progress report.

Interferon-alpha therapy causes complete remission in about 50% of polycythemia patients, but it often has serious side effects that force patients to stop using it.

Researchers can improve the effectiveness of interferon-alpha treatment and significantly reduce the toxic side effects if they can identify the specific molecules it acts on that are responsible for triggering the body's immune responses. We call these molecules antigens.

By applying new technology, Dr. Yang's team has already discovered four new tumor antigens in patients with PV. But that is only the first step. They are now in the process of learning about these new tumor antigens and how they cause tumor fighting responses as a result of treatment with interferon-alpha. This may lead to new, antigen-specific generations of immune therapies that work more effectively and cause fewer side effects.

## TEE TIME COMING UP FOR SUPPORTERS OF MPD RESEARCH

*Friends of ET Research 5<sup>th</sup> Annual Golf Classic Tournament to Be Held Tuesday, September 14<sup>th</sup>*

Join Celia Miltz and family at a truly impressive fundraiser for MPD research – not to mention a truly fun event. This year's tournament will be held September 14<sup>th</sup> at the lovely Centennial Golf Club in Carmel, New York. If you're anywhere in the area, mark it on your calendar!

For more information, visit [www.friendsofETresearch.org](http://www.friendsofETresearch.org).

## DIRECTING LLS DONATIONS TO SUPPORT MPD RESEARCH

Yes, if you're making donations to the LLS, you can specify the area of research you want to support. Just include your instructions in a letter that you send with your check to your local LLS chapter. Also make a notation on the "Memo" line on the check.

If you're collecting donations from others, each donor must provide instructions requesting that their funds be directed to MPD research.

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

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