



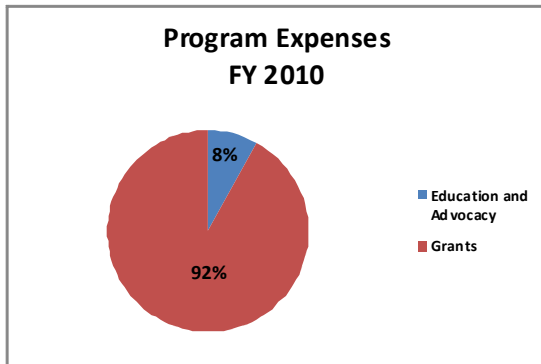
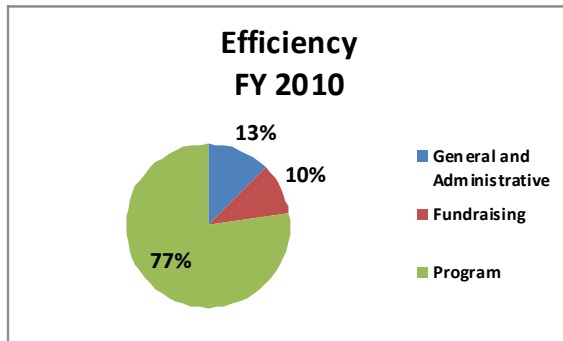
## ANNUAL REPORT 2010

## PRESIDENT'S REPORT

By Barbara Van Husen

In 2010 the MPN Research Foundation increased its efficiency from years past while also extending its work in the MPN research and advocacy world. We are exclusively dedicated to funding MPN research and advocacy for polycythemia vera, essential thrombocythemia and myelofibrosis. Some of our notable achievements this year include:

- Maintained the Better Business Bureau's Wise Giving seal of approval for charities
- Funded 8 MPN grants
- Oversaw an RFP for New Investigator and Established Investigator research grants
- Hosted 2 MPN patient symposia



MPN Research Foundation's primary mission is to stimulate original research in pursuit of new treatments and eventually a cure for polycythemia vera, essential thrombocythemia and myelofibrosis. In addition MPN Research Foundation promotes collaboration in the scientific community to accelerate MPN research, and serves as a powerful advocacy group for patients and their families.

While our priority remains on funding innovative and accountable research we have also increased our efforts to educate and empower the MPN community of patients, family members, doctors and researchers. Funded by patients, for patients, we will continue to prioritize the needs of the MPN patient community.

## STATEMENT OF ACTIVITIES

	2010	2009
<b>Revenues and other support</b>		
Contributions	\$1,233,523	\$1,289,948
Investment Income	14,065	8,848
Net assets released from restriction	<u>94,281</u>	<u>176,333</u>
Total Revenues and Other Support	<u>1,247,588</u>	<u>1,298,796</u>
<b>Expenses</b>		
Program	1,124,538	1,055,507
General and Administrative	181,730	185,519
Fundraising	<u>146,692</u>	<u>158,008</u>
Total Expenses	<u>1,452,960</u>	<u>1,399,034</u>
<b>Changes in Net Assets</b>	(288,991)	(100,238)
<b>Net Assets</b>		
Beginning of year	<u>1,075,154</u>	<u>1,175,392</u>
End of year	<u>\$869,782</u>	<u>\$1,075,154</u>

## PROGRAM SERVICE ACCOMPLISHMENTS IN 2010

2010 was a year of major breakthroughs in MPN science, and saw the advancement of clinical trials that may result, as early as 2011, in the first new treatments for MPN patients in decades. The MPN Research Foundation (known until 2011 as 'The MPD Foundation') is proud of its contribution to this amazing progress. This report summarizes the achievements made and the new opportunities identified in 2010 by the MPN Research Foundation on behalf of all MPN patients.

### Research

The Foundation continued to monitor **8 current academic research grants** (awarded by the Foundation in 2009) as the second year of funding for these grants expanded and validated the hypotheses proposed by each of the principal investigators. Highlights of these projects include:



*Ann Mullaly at the lab*

- The identification of 2 new genes related to MPNs and often correlated with transformation to acute myeloid leukemia by **Robert Kralovics (Center for Molecular Medicine, Vienna Austria)**
- Publication of multiple studies based on the MPN Research Foundation (formerly MPD Foundation) -funded clinical database and cell and plasma bank at the Mayo Clinic. These studies have validated the results of gene studies and the prognostic relevance of the genes identified, and has led to fundamental changes in MPN disease classification and diagnosis, as endorsed by the World Health Organization. (**Ayalew Tefferi, the Mayo Clinic**)
- Development of a sensitive clonality assay to be used in assessing changes in the expression of genes when PV patients are treated with Pegasys in an upcoming (2011) randomized Phase 3 clinical trial (**Josef Prchal, University of Utah**)
- Study of the molecular basis for treating MPNs with Pegalated Interferon (Pegasys) in anticipation of the 2011 randomized Phase 3 study of this drug in polycythemia vera patients (**Ron Hoffman, Mt. Sinai**)
- Validation of mutations in novel genes which are altered in MPNs using an integrated genomic approach, and a study of the genetic basis of familial MPNs (**Ben Ebert, Brigham and Women's Hospital**)
- Establishment of the precise frequency of the TET2 gene mutation, and its correlation with MPN disease phenotype (**Francois Delhommeau, Inserm, Paris, France**)

In addition, the Foundation began the search for proposals for its **next round of research grant awards**. Proposals were solicited in 2 categories:

- **New Investigator Awards.** Two-year grants of \$75,000 per year. These grants are aimed at emerging investigators who are considering a career related to research in the

myeloproliferative neoplasms (MPNs) or established investigators in other fields who are interested in bringing their experience, skills and ideas to research in the MPNs.

- **Established Investigator Awards.** Two-year grants of \$150,000 per year. These grants are aimed at researchers with a demonstrated interest and history of achievement in MPN research. Projects can be either basic or translational research, as long as results will contribute to new understanding, new molecular targets, or new treatments for MPNs.

A total of 43 proposals (24 New and 19 Established Investigators) were received in response to this request for grant applications. During the fourth quarter of 2010, the proposals were evaluated by a distinguished panel of 19 MPN scientific experts. Final awards based on these recommendations will be made early in 2011.

In preparation for the new grant awards, the Foundation also initiated a study of the **potential impact of full genome sequencing** to identify new drug targets. Opportunities to ensure that genome data is made available for study by all qualified researchers were studied in detail, leading to the Foundation's decision to fund genome research only if the resulting data were deposited into dbGaP, a new central, sharable repository managed by the National Institutes of Health (NIH). The Foundation is proud to be one of the first research foundations to mandate this sharing of genome data.

### **Education and Advocacy**

The Foundation hosted two patient symposia in California (San Mateo and San Diego) to bring information on the state of MPN science to patients on the West Coast, and began planning for a major upgrade to the Foundation's website to be implemented in 2011. The Foundation's Board of Directors also approved several significant advocacy programs for implementation in 2011, including development of MPN Centers of Excellence, a Chicago-based Roundtable of MPN clinicians, and a study defining the potential of developing an MPN Patient Registry.

The Foundation remains committed to educating patients through its free semi-annual newsletter, as well as assisting with coordination of patient support groups in the U.S. and abroad. In addition, the Foundation actively seeks to connect with physicians worldwide to provide the information and support they need for both clinical practice and patient support.



*MPN patients gather after a support group meeting in San Francisco*

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