



VOLUME XVIII, NO. 2 FALL 2019

PERIODIC NEWSLETTER FOR THE MYELOPROLIFERATIVE NEOPLASMS COMMUNITY

ANNOUNCING OUR 2019 MPN CHALLENGE GRANT AWARDEES

Rick Winneker, PhD, Director, Strategies & Research Operations

This past January, MPN Research Foundation (MPNRF), with support from The Leukemia & Lymphoma Society announced the 2019 MPN **Challenge Grant Program**, whose objective is to stimulate innovative and clinically relevant research that has the highest potential for nearterm patient impact. We do this by expanding our understanding of both the basic biology of MPNs and what is driving the development and progression of disease, and by addressing critical gaps slowing the development of new therapeutic approaches.

A few research topic areas of interest highlighted in this announcement were:

- 1) Immunotherapeutic approaches for MPNs
- 2) Targeting the driver mutations associated with MPN
- 3) New mechanisms of drug action
- 4) Repurposing existing FDA-approved drugs for use in MPN
- 5) Development of biomarkers of disease progression
- 6) Stem cell transplantation
- 7) Quality of life research

We received 43 grants from 7 countries worldwide. After meeting in July, the peer review panel's recommendations were recently approved by the MPNRF Science Steering Committee.

The following grantees have been offered 2-year grants with a maximum \$100,000/year award:

Matyas Ecsedi, MD, PhD, Fred Hutchinson Cancer Research Center. A JAK2 V617F - directed T cell receptor transgenic T cell immunotherapy for the treatment of myeloproliferative neoplasms. Support for the first year of this grant will be partially provided by the Fred Hutchinson Cancer Research Center Evergreen Fund.

Yelena Ginzburg, MD, Tisch Cancer Institute, Icahn School of Medicine at Mount Sinai. Dysregulated iron metabolism plays a pivotal role in polycythemia vera.

Vikas Gupta, MD, Princess Margaret Cancer Center, University Health Network. Feasibility of a patient preferences-controlled study of allogenic hematopoietic cell transplantation versus best available nontransplant therapies in patients with myelofibrosis (ALLO-BAT Study).

Catriona Jamieson, PhD, University of California, San Diego. Detection and Inhibition of Malignant RNA Processing Deregulation in Myelofibrosis.

Alison Moliterno, MD, Johns Hopkins University School of Medicine. Targeting Thrombopoietin Signaling in the MPN.

Jyoti Nangalia, PhD, Wellcome Sanger Institute. *Origins of MPN*: Understanding the timing of acquisition of driver mutations and dynamics of clonal expansion.

Vijay Sankaran, MD, PhD, Boston Children's Hospital. Dissecting Germline Genetic Risk for Myeloproliferative Neoplasms. ■



TOP ROW: Matyas Ecsedi, Yelena Ginzberg, Vikas Gupta, Catriona Jamieson BOTTOM ROW: Alison Moliterno, Jyoti Nangalia, Vijay Sankaran

MISSION

The primary mission of the MPN Research Foundation is to stimulate original research in pursuit of new treatments — and eventually a cure — for myeloproliferative neoplasms (MPNs). In addition, the MPN Research Foundation promotes collaboration in the scientific community to accelerate research and serves as a powerful patient advocacy group for patients and their families.



CHANGE YOUR PROGNOSIS

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MPN RESEARCH FOUNDATION UPDATE

A periodic newsletter published by the MPN Research Foundation to provide members of the MPN community with information on current research and the Foundation's activities.

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CLINICAL TRIAL HIGHLIGHTS



Research on myeloproliferative neoplasms has picked up heavily over the last few years. There are several MPN clinical trials under way. The trials listed below are currently enrolling patients and may be of interest. A complete list can be found on our website: www.mpnresearchfoundation.org/Clinical-Trials.

CPI-0610, Ruxolitinib

Sponsor: Constellation Pharmaceuticals Contact: Debbie Johnson | 617-714-0555 Diagnosis Type: Myelofibrosis

KRT-232 vs Ruxolitinib

Sponsor: Kartos Therapeutics, Inc.

Contact: John Mei

650-542-0136 | jmei@kartosthera.com **Diagnosis Type:** Polycythemia Vera

Oral Rigosertib

Sponsor: MD Anderson

Contact: Jorge Cortes | 713-794-5783 Diagnosis Type: Myelofibrosis

Ruxolitinib + Pevonedistat

Sponsor: Washington University School

of Medicine

Contact: Stephen Oh, M.D., Ph.D. 314-747-7960 | stoh@wustl.edu Diagnosis Type: Myelofibrosis

CALR Exon 9 Mutant Peptide Vaccine

Sponsor: Inge Marie Svane
Contact: Jacob H. Grauslund, MD
452-010-4504 | jgra0033@regionh.dk
Contact: Hans Hasselbalch, MD

454-732-4800 | hkhl@regionsjaelland.dk **Diagnosis Type:** Essential Thrombocythemia,

Myelofibrosis

Ruxolitinib + Chemotherapy

Sponsor: City of Hope Medical Center Contact: Haris Ali | 626-256-4673 Diagnosis Type: Myelofibrosis ■



Bill Crowley, Director of Development

MPN patients and their families are a remarkable and impressive group. The creativity they show to raise funds to support research is inspiring. They sell pizzas, pledge their birthdays, and sponsor fun runs and walks. One patient's family member wanted to raise money for the foundation by participating in a charity bike ride. She didn't even own a bike!

As a representative of the MPN Research Foundation, I'm honored to have had the opportunity to meet many outstanding and interesting people. One of my first visits was with a MPN patient named Susan Protter in New York city. Susan was a co-leader of the New York Patient Support group. Susan had a very interesting life. She edited publications for

(CONTINUED ON PAGE 7)

THE VALUE OF YOUR MPN EXPERIENCE

...How myMPN data is used in the research pipeline

Lindsey J. Whyte, Longitudinal Research Project Manager

The success of myMPN has been overwhelmingly positive and it is all because of patients like you! Have you visited the registry lately to fill out a How Do You Feel, Today? survey or to record a recent event such as a blood draw or medicine change? Our poster at the European Haematological Association meeting in June showed how the genetic profile of your blood may be linked to the severity of the symptoms you experience. Other data shared at past conferences compared the symptom profiles of myMPN participants based on their current diagnosis and the medicine they take, if any. What does this data sharing accomplish?

WHAT CAN LABORATORY RESEARCHERS LEARN FROM YOUR REAL WORLD DATA?

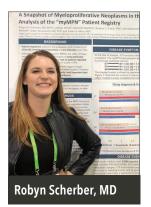
Laboratory researchers seldom have access to patients and rely often on clinician researchers to relay the patient experience. When potential new drugs are identified to test for a beneficial effect on patients with a specific disease, it is typically done based on the best science available at the time. The more information available to researchers on the front end about genetic profiles of patient's disease, the symptoms they experience, and their previous responses to certain medicines, the better equipped researchers are to make hypotheses about potential treatments for them. This is one of the reasons why we try to share myMPN data at conferences.

WHAT HAPPENS AT CONFERENCES?

There are several major conferences each year worldwide that draw clinicians, researchers and biopharma industry representatives together. For example, the American Society of Hematology hosts a conference every December that is attended by approximately 25,000 participants from all over the world. This is the preeminent meeting for anyone working in hematology research, clinical care and drug development or support services. It is an opportunity for researchers to present their latest findings and for formal and informal gatherings to take place where collaborations are formed. Clinicians share their best practices, challenging patient cases may be discussed, and plans are made to make progress in the year ahead.

Some of what happens at the conferences is commercial in nature. For example, drug companies host booths in the expo hall where they highlight their current therapies and the benefits they offer patients. They may also host events for clinicians and advocates to get together for educational or social purposes. Other events at conferences are strictly focused on reporting progress of research and/or clinical trials. Some presentations are for thousands of people and some are directed at smaller audiences.

The agenda of the conference is typically decided by a committee of experienced scientific and/or medical volunteers, who attend the meetings regularly. During the December 2018 ASH meeting in San Diego, a German researcher presented data about studies conducted on stem cell transplant timing to a room of around 300 conference participants. This type of presentation is ideal for young clinicians who may see some MPN patients and want to keep up to date on the research, as well as MPN-focused clinicians and researchers who are following all developments closely.



In addition to formal talks presented by researchers, clinicians, and other experts involved in clinical trials, new data is also presented during poster sessions. Imagine a massive room where rows upon rows of 4' by 6' stands are located, each with a poster highlighting an area of scientific inquiry pursued by the researcher or clinician standing in front. They answer questions and gather feedback from various experts, clinicians or colleagues who happen to pass by. After the poster session, they

report back to their team of collaborators and a decision may be made whether to move forward, change the course of the research, or discontinue it altogether. Pictured here is Robyn Scherber, MD, a myMPN Steering Committee Member and clinician at UT Health presenting a poster featuring myMPN data at the recent American Association for Cancer Research Meeting.

WHAT ROLE DOES MYMPN DATA PLAY IN THE BROADER PICTURE OF MPN RESEARCH?

As the volume of data increases in myMPN, our ability to formulate hypotheses and test them increases and this, in turn, feeds the broader MPN research pipeline. Researchers can use myMPN data to formulate their assumptions, support their conclusions or simply to compare it to what they've seen in a similar study. Clinicians can use insights from myMPN to ensure that their recommendations to patients meet best practices based on the experience of a much larger group of patients with similar diagnoses and symptoms.

The most important thing to remember is that, without patients providing data, myMPN is just an empty repository. Don't forget to log in to myMPN and update your profile with the latest on how you are feeling and any recent events in your health so that the value of the data within that repository continues to grow! If you haven't yet started with myMPN, there's no time like the present – visit the registry at www.myMPN.org or www.mpnrf.org/mympn-register!

SCIENTIFIC SESSION TURNS RESEARCH FOCUS TO THROMBOSIS AND MPNS

Barbara Van Husen, Board of Directors, Chair

On June 27-28, a multi-disciplinary MPN meeting was held in Charleston, South Carolina. The focus of this meeting, organized by Drs. Ron Hoffman, Andrew Schafer and Ruben Mesa, was the cause(s) and treatment of thrombosis in MPN patients. When asked why this meeting was important, Dr. Schafer said the following: "We created this meeting because thrombosis, vascular and bleeding complications are the leading causes of morbidity and mortality in the MPNs. Yet there has been very little attention paid to understanding the reasons for these complications and to treating or preventing them."

The three convened an international group of experts in the MPNs and experts in vascular and thrombotic diseases to address the issue from a multi-disciplinary perspective. What became evident is that the MPN experts and the thrombosis experts didn't know each other, and in some ways didn't speak each other's scientific or medical language. In addition to listening to major breakthroughs in both arenas of research and participating in highly enlightening interdisciplinary discussions about them, MPN and thrombosis participants were "caught" in private discussions on the sidelines germinating ideas for future clinical research collaborations for the first time.



Participants at a multi-disciplinary MPN meeting in Charleston, South Carolina; A presentation on stem cell transplant timing.

Dr. Schafer summarizes the importance of this meeting as follows: "The bottom line from this meeting, in my opinion, was this: A major reason for why such little research has been done to address these problems is that the thrombosis people were assuming that the MPN people were doing it, and the MPN people were assuming that the thrombosis people were doing it. The result of course is that virtually nobody was doing it. Plans now are to write up the issues discussed for publication, and to also seriously consider having another conference on this in a year or two to follow progress if we can get funding for it."

For more information on the agenda and speakers for this meeting, see https://www.eventsquid.com/event.cfm?id=6239. ■

MPN DISEASE PROGRESSION EFFORTS CONTINUE

Rick Winneker, PhD, Director, Strategies & Research Operations

The progression of a myeloproliferative neoplasm to a more aggressive state is one of the greatest concerns for patients. In addition to addressing disease progression through proposals that are submitted to our MPN Challenge program, we have been actively seeking other avenues to drive breakthroughs in this area. After months of diligence and input from many stakeholders, including advisors Drs. John Crispino, Raajit Rampal and Serge Verstovsek, we have decided that we are not ready to build a large biobank of patient samples and clinical data at this time, given the cost and fast pace of progression research.

For the time being, we have turned our attention to smaller, targeted projects where our dollars and convening power can have greater impact. In early June, we gathered an outstanding group of progression researchers (Drs. Ross Levine, Alison Moliterno, Ann Mullally, Jyoti Nangalia, Naseema Gangat, Hans Hasselbalch, Umberto Gianelli, and Paolo Guglielmelli) to discuss research gaps and possible solutions.

Several high-level recommendations are currently under consideration, such as capitalizing on the use of existing data through collaborations convened by the MPNRF, and encouraging more academic/biopharma efforts toward disease modifying therapies. One pilot project relevant to progression has recently been approved by the MPNRF Science Steering Committee. That grant of \$85,000 has been awarded to Dr. Ann Mullally, Brigham & Women's Hospital, to support the integration of clinical/patient information with gene profiling data already completed at Dana-Farber for around 1,000 MPN patients, and for future patients as well. This will allow for a greater use of gene profiling in predicting patient outcomes and treatment decisions, and help build a more valuable resource for integration and comparison with other databases in the future.



MEET THE MPN WOMEN WARRIORS MAKING A DIFFERENCE ONE STEP AT A TIME

Jennifer Acker
Content Writer for MPN Research Foundation



"BOB ROSEN'S DEATH FROM HIS MPN WAS MY IMPETUS TO START MPN PEORIA."

Eight years ago, at 40 years old, Michele Couri was diagnosed with PV. Over those eight years, she often sought the advice of the late Bob Rosen, founder and former President of MPN Research Foundation. It was the advice of her late mentor and friend that has stayed with her: "He told me that I would know when the right time would be. His message is my message as well. When you are ready to truly dedicate yourself to this cause, nothing can stop the momentum. It will come naturally and from the heart."

2019 was the year Michele created "MPN Peoria." The first annual MPN Peoria Hike took place on June 22 at Forest Park Nature Center in Peoria, Illinois, Michele's hometown.

A hiking event was an easy choice for Michele, who loves the meditative and restorative qualities that spending time in nature provides.

Michele is a full time practicing OBG/YN, mother of six, and PV patient, but still managed to find the time to organize a very successful hike that raised \$59,500 and had 425 registered participants. "I don't have a background in fundraising, but my cochair Mary Walsh does, so she was absolutely invaluable. Without her, none of this would be possible," she says.

Michele is also inspired by her patients, community, and family who

showed up to support her and everyone else living with an MPN. "The day of the hike was truly one of the most memorable of my life... looking out over the crowd of hundreds of hikers and realizing that all these wonderful, caring and generous people came to support all of us living with MPNs was unforgettable."

Michele's advice to the MPN community: "Don't be afraid to put yourself out there and be vulnerable. Starting MPN Peoria was a risk, but I was willing to take that risk so that I can make a difference in the lives of MPN patients." And that she did. Thank you, Michele Couri.

"I DON'T FEEL HELPLESS WITH THIS DISEASE, I FEEL EMPOWERED."

Hikers have come from as far away as California, British Columbia, and England to show their support for "Hike MF," an annual event that takes place at Borderland State Park in North Easton, Massachusetts. Sisters Lori Small and Julie Libon, only 17 months apart in age, have always been close, so it was no surprise that when Julie was diagnosed with MF in 2014 her sister Lori was ready to help her organize and plan Hike MF.



"It was just a matter of days after my diagnosis that we decided to host a hike. We grew up hiking in the mountains of New Hampshire, Maine, and Vermont, so we thought a hike would be an homage to our parents. We thought we'd raise a few hundred dollars and have about 25 people show up at the first hike. We figured if we had music and food people would be happy. Well, it worked. We had 125 people sign up that first year and raised \$25,500. Lori set the high standard that year for how Hike MF would run," Julie says.

(CONTINUED ON PAGE 6)

MEET THE MPN WOMEN WARRIORS (FROM PAGE 5)

Julie credits Lori with the hike's continued success, which the sister duo has hosted for five years. They've planned the event each year like they would plan a party. Their goal has been to make sure participants have fun, feel welcome and of course raise money for research.

"Without Lori, Hike MF would not exist. I'm so fortunate to have Lori as my sister, who I consider the strongest, most caring, and loyal person., says Julie. And Lori will help her dear sister for as long as it takes. "I continue to organize and participate in this event because there isn't a cure yet for MPN's." Lori says.

Julie and Lori's positive and take-charge attitudes have made a difference. In the five years since Julie has been diagnosed, Hike MF has raised close to \$190,000 for MPN research.

"It's not that difficult to make a difference and putting my energy towards helping others has helped me. I don't feel helpless with this disease—I feel empowered," Julie says.







PROVIDING EDUCATION AND RESOURCES FOR A BETTER TODAY. INVESTING IN RESEARCH FOR A BETTER TOMORROW.

Partner. Advocate. Friend. At the MPN Research Foundation, we're committed to standing with you in the fight against polycythemia vera (PV), essential thrombocythemia (ET) and myelofibrosis (MF) — the group of blood cancers collectively known as myeloproliferative neoplasms.

WWW.MPNRESEARCHFOUNDATION.ORG



SOCIAL MEDIA: REACHING PATIENTS ONE POST AT A TIME

With the help of the vast communities and global networks that social media has created, patient advocacy groups, like MPNRF, can engage directly with patients in real-time.

The opportunities and benefits of communicating with patients through social media are endless. At the MPN Research Foundation, we can provide breaking news updates about research and treatments and information about upcoming events and webinars from all over the world. Patients and caregivers can join virtual communities where they're able to ask questions and feel supported by peers. Participating in research is also a breeze; it's possible to partake in online surveys or studies from the comfort of their own home.

As patients turn to online resources, it's vital that advocacy groups continue to use social media to provide access to credible health care information. This includes educational materials, doctorapproved sources, and more.

Of course, social media isn't the only tool we use to reach patients. There are also blog posts, webinars, forums, educational videos, published articles - the list goes on and on. These platforms, in partnership with social media, are redefining the way people communicate. In health care, it's redefining how patients communicate: with each other and with the advocacy groups that represent them.

If you're interested in joining an online community or learning about the latest news, follow us on social media by using our handles below, and don't forget to visit the MPN Research Foundation's website at www.MPNRF.org to see our ever-growing list of online patient communities.



MPNRESEARCH



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Pam Soto

FIGHTING MPNS, MAKING MOMS PROUD

Pamela Soto. Director of Individual and Major Giving

As a new member of the MPNRF's team, I am honored to be part of an organization that is committed to funding research dedicated to finding a cure for MPNs. After my mom was diagnosed with

Polycythemia Vera more than five years ago, I became aware of how much more research and resources are needed towards finding a cure.

My focus as the new Director of Individual and Major Giving is to continue building our individual and major donor giving program. Building donor relationships as well as cultivating new relationships will advance our ongoing efforts to raise funds for research. It's vital to our organization to help reach our fundraising goals and meet the unmet needs of communities living with MPNs. My experience working across a range of industries, including large hospital systems, non-profits, consumer goods, and health care, has shown me that developing and maintaining relationships is the key to an organization's strength.

By continuing to dedicate our efforts to raising funds, we can better address our patients' needs and keep those involved in research moving in the right direction. I'm hoping one day there may actually be a cure for patients diagnosed with MPNs. Wouldn't that be a wonderful thing, and that I may have had a small part in an effort dedicated toward that very goal? I think my mom would be proud.

If you are interested in raising funds for MPN Research Foundation, please reach out to me at psoto@mpnrf.org or (312) 683-7249.



FROM PAGE 2

larger publishing companies. Part of her job involved extensive travel and meeting with many remarkable people. Sue shared all kinds of interesting stories about her travels and the people she met.

Unfortunately, Susan had a number of health issues. In addition to her PV, which was diagnosed over 20 years ago, she attended cardiac rehab for a number of months. She had vision problems, hearing issues and walked with a cane. Despite all these health issues, Susan insisted on continuing in her role as co-leader. Over time, Susan's sight was so bad that she couldn't read email. She also couldn't hear, so when I called, I spoke to her caregiver who somehow relayed the message.

PLAN A GIFT THAT WILL GIVE HOPE

Unfortunately, Susan passed away late last year. But she still supports MPN research because Susan included the Foundation in her estate plans. Because of the size of her gift, we are establishing the Susan Ann Protter Research Fund, per her family's wishes. This year and for many years to come, she will still be supporting the research we fund to find better treatments and a cure for MPNs.

If you are thinking about your estate plans but are unsure how to start, we can help. Visit our website at http://www.mpnresearchfoundation. org/Include-MPNRF-in-Your-Estate-Plans and realize your legacy. ■

WHAT WAS BURIED

Jennifer Acker Content Writer for MPN Research Foundation

For Merle Wertman of Tamaqua, Pennsylvania, there never were any answers-only more questions. In 2003, he was diagnosed with polycythemia vera (PV), a rare progressive incurable blood cancer that affects the bone marrow. But Merle's diagnosis is not rare in northeastern Pennsylvania. In fact, the tri-county area of Carbon, Luzerne and Schuylkill counties is the first region in the country to be recorded as a PV "cluster". A diagnosis of PV puts a patient at higher risk of stroke, heart attack, thrombosis, and in some cases, can progress to life-limiting myelofibrosis or leukemia. Studies have also suggested that exposure to toxic substances and high levels of radiation can increase a person's likelihood of being diagnosed with an MPN¹. The average general practitioner may only see a few cases of PV in his or her lifetime, making it a difficult disease to diagnose and treat.

Merle Wertman

The PV cancer cluster in Northeastern Pennsylvania is home to three Superfund sites, abandoned strip mines, and a coal-fired power plant. Merle and his wife Linda have lived in the afflicted region of Tamaqua since 1969. In a recent interview, Merle shared that there are thirteen other cases of rare cancers on his small block, and seven residents who have since passed from cancer (not all MPNs) on the street. While he can't prove it, he has a strong suspicion that his drinking water, which comes from the Still Creek Reservoir, has made himself and many others on his block sick.

The higher rate of PV diagnoses in Northeastern, PA relative to the general population first caught the attention of internist Dr. Peter Baddick nearly fifteen years ago. At that time several residents from Ben Titus Road in Rush Township had been diagnosed with PV. In one case, a husband and wife from the same household were both diagnosed with it. Ben Titus Road runs parallel to the Still Creek Reservoir, and the reservoir is near a superfund site in McAdoo, where toxic waste and coal ash were buried in mine shafts, after a mining company was discovered illegally burning and dumping toxic waste during the 1970s. High levels of cancer-causing Benzene were found at the site, along with dead wildlife.

The number of patients in Northeastern PA with a rare blood cancer was alarming enough for then-Senator Arlan Specter to spearhead a campaign more than a decade ago to secure federal funding for the study. Soon after, the Center for Disease Control (CDC) and the Agency for Toxic Substances and Disease Registry (ATSDR) conducted a federal study that encompassed Luzerne, Carbon and Schuylkill counties². However, the only conclusion from the study was that the tri-county region had a four times higher rate of polycythemia vera

"WE HAVE GRANDKIDS AND GREAT-GRANDKIDS WHO LIVE IN THE AREA. I DON'T WANT ANY OF THEM TO GET SICK BECAUSE NOTHING HAS BEEN DONE."

than the national average. During the study, investigators told citizens it would be impossible to pin a cause on the PV.

Ann Brazeau, CEO of MPN Advocacy and Education International, spent a great deal of time engaging the CDC and local citizens in the tri-county area gathering information on the PV cluster while at the MPN Research Foundation. Ms. Brazeau and Dr. Ronald Hoffman of Mount Sinai traveled to the area for a town hall meeting that ended in frustration.

"I was thrilled when Senator Specter crossed the aisle to the Dems and was able to convince the Obama administration to appropriate \$5M per year to investigate this obvious cluster," Ms. Brazeau says. "Diagnostic programs were implemented in the area that confirmed the PV cluster existed, but to my knowledge, nothing further was done. We know that certain chemicals were dumped into empty mine shafts and those were designated Superfund sites. Some of the chemicals were also used in Agent Orange."

For Merle Wertman, the questions are many and the answers are few. He wants to know who is responsible for this environmental disaster. Another concern from the community is whether a cluster of PV persists.

"We have grandkids and great-grandkids who live in the area. I don't want any of them to get sick because nothing has been done," he says. For the affected residents of the tri-county area, there is no cure for PV or closure from the investigation, only frustration and mounting anger.

Merle will continue with his monthly phlebotomies to prevent his red blood cells from becoming too thick. He will live with the physical limitations of PV: extreme fatigue and migraines. He will miss out on some walks to the park with his grand and great-grandchildren because he's too tired. And he'll continue to wonder why nothing has changed in this town, where secrets are buried like toxic waste.

CITATIONS:

- 1. Verstovsek, et al. Int J Gen Med. 2014; 7: 89–101 Myelofibrosis-associated complications: pathogenesis, clinical manifestations, and effects on outcomes
- Cole, et al. Int J Environ Res Public Health. 2010 Mar; 7(3): 1139–1152.
 A Multidisciplinary Investigation of a Polycythemia Vera Cancer Cluster of Unknown Origin