

**Summer 2025** 

Cancer Research & Treatment Fund, Inc.
Established 1968

Funding Cancer Research: Innovative. Agile. Experienced.



One of the greatest ongoing challenges to more meaningful MPN research is not a lack of information, as is often described. To the contrary, there may be too much information to humanly gather, sort and assemble so that it is available as usable data for studies.

While hospitals must maintain electronic medical records by law, this overwhelming amount of patient data is not organized in any useful way for research. Joseph Scandura, MD, PhD, physician scientist, Associate Professor of Medicine at Weill Cornell Medicine (WCM) began to imagine if it was.

WCM has a robust information technologies resources program, including Architecture for Research Computing in Health (ARCH) – a suite of tools and services designed to help investigators extract and analyze electronic patient data.

"I saw an opportunity to transform this untapped resource into a powerful tool for our MPN (myeloproliferative neoplasm) research," explains Dr. Scandura, who first

envisioned The Richard T. Silver MD MPN Center Research Data Repository (RDR) and worked to make it a reality. "The RDR is the foundation of our research infrastructure—an 'office' where all MPN data is systematically organized, and accessible for advanced analysis."

While the RDR isn't new, it is an ever-evolving tool that continues to grow in its applications, delivering on thought-leading answers to some critically important MPN questions, both new and old.

"Basically, every paper that's come out of the Silver MPN Center at Weill Cornell Medicine in the past six or seven years has entirely used this infrastructure," including both basic laboratory and human "translational" research, according to Dr. Scandura. "So, it's really the hub around which all of our MPN-related research revolves."

(cont. on page 2)

# **Financial Patient Assistance Programs for MPNs**

The World Health Organization (WHO) published a revised document in 2008 listing MPNs as a blood cancer to promote the recognition of the genetic characterization of myeloid malignancies. Now, there are numerous organizations providing financial support and assistance with travel to a cancer center, copay and medication assistance, and many programs for patients with an MPN blood cancer.

For the newly diagnosed [patient], one of the first recommendations is to see an MPN specialist. Financial burden can make this a difficult task. Even with healthcare insurance, the deductibles and copays can make this task financially overwhelming. Here's a "doctor reviewed" and frequently updated list of MPN Specialists in the United States to find a specialist close to you. https://www.pvreporter.com/mpn-specialists-cancer-treatment-centers (cont. on page 6)

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### Real World Example: Polycythemia Vera

If you look at polycythemia vera (PV), modern studies are based around endpoints that are about controlling blood

counts, in particular, avoiding thrombosis (blood clots). This is not unreasonable, admits Dr. Scandura. "But we know that even when people's blood counts are perfectly controlled, they still have an excess risk of blood clots. And so if we're ever going to reduce that, we need to be able to figure out who those people are (who are at greatest risk), then figure out things we can do to help them."

"I saw an opportunity to transform this untapped our MPN (myeloproliferative neoplasm) research."

- Joseph Scandura

resource into a powerful tool for

to ask questions about the things we care about the most."

"The RDR essentially organizes the chaos of electronic medical records data into research-ready or analysis-ready

> datasets," explains clinician/scientist Dr. Abu-Zeinah, also broadly recognized for his work in the field of MPNs. "It has a tremendous impact by automating and thereby facilitating the extraction of clinical record data. Querying and analyzing clinical data is now streamlined by the RDR, allowing us to test several hypotheses within minutes to hours."

Sticking with polycythemia vera, Dr. Abu-Zeinah adds perspective.

If a new study was designed, it would need participation by thousands of patients over a number of years and at significant expense - not likely when only a small percentage of PV patients actually develop a clot each year. Yet over time, they have a significantly greater chance of developing both arterial and venous thromboses.

Enter the world of big data. Weill Cornell Medicine has every lab report of anyone who has ever had bloodwork there. That's tens of thousands of pieces of information. "We have every bone marrow report, and the bone marrow is turned into some 30 columns of data ... every bone marrow times 30 points of information," explains Dr. Scandura. "We have every vital sign they ever had done, a record of every time they got a transfusion or had a phlebotomy, or every molecular test they ever had. So when you take all of that and you stuff it into a big model and use modern approaches that could handle that kind of data, machine learning, et cetera, you can start asking different questions."

And that's exactly what they do, continually.

Still using the PV and clotting example, Dr. Scandura, along with Ghaith Abu-Zeinah, MD, and others, asked this: can we develop a model that based on all of this information predicts whether at each clinical visit a specific patient is likely to have a clot within the next year? "This is a short time, an actionable period of time," Dr. Scandura explains.

So they built a model to find out. They started with about 10,000 columns of data for each patient from each visit. Multiply that by every visit since each patient began coming to Weill Cornell Medicine. Reducing the number of individuals to 300 patients still gave them millions of pieces of data.

### One Giant Leap for Al

The team then used sophisticated AI (artificial intelligence) to help them identify exactly what to look at. They asked: "What are the pieces of information that are important to predict a clot, and how well can we predict it? So, it turns out it works remarkably well," Dr. Scandura shares, "It becomes very enabling "Our impactful, frequently cited study on long-term outcomes of interferon treatment in PV was a product of this effort. The study identified survival advantages with interferon, long predicted by Richard T. Silver, MD. Our new findings will have a tremendous long-term impact on patient care. In fact, a follow-up study we published indicated a normal life expectancy is possible for patients with PV treated with interferon. It also highlighted preventable mortality from PV in the United States, for which more awareness and referral to centers of expertise is needed."

In the case of the Research Data Repository, alongside these extraordinary researchers is AI, another hero in the story of how to learn what we're not asking.

"Al is capable of learning in seconds what we learn in years," says Dr. Abu-Zeinah. "And if we train it well, it will accelerate our research and discovery of curative cancer treatments."

Ruth Fein Revell is a freelance health and medical writer. 30-year MPN patient, and author of The Big C2 - stories from the chronic side of cancer. Ruth was the Cancer Survivor Honoree at CR&T's Cancer Survivors Hall of Fame Dinner in 2024.

The Richard T. Silver, MD Myeloproliferative Neoplasms (MPN) Center at Weill Cornell Medicine is the cornerstone of CR&T's research strategy, providing a multi-year, \$8 million grant to this translational research and treatment center.

CR&T's support is key to building and sustaining a worldclass center that focuses exclusively on these rare blood cancers, which can cause serious - and sometimes lifethreatening - complications.

The Research Database Repository is foundational to the clinical and laboratory research at the MPN Center. Through contributions from donors like you, CR&T is proud to support innovative research techniques like this at the Richard T. Silver, MD MPN Center.



Dear Friends,

I'll be honest - there are days when the slow pace of progress in cancer research can feel like walking uphill through fog. The breakthroughs are real, but they rarely arrive with the speed or clarity we wish for. In a world that moves at the pace of abbreviated headlines and instant gratification, it's hard to explain how progress in this field often means months of methodical work for insights that slowly emerge. And yet, this is the nature of meaningful change. Cancer does not yield to quick fixes. Every data point, every clinical trial, every small win is a brick in the foundation of something enduring.

During these times, we are pleased to relay the tremendous optimism of CR&T-associated physician-researchers who, in the last 16 months alone, have published over 20 peer-reviewed papers and had over 25 abstracts accepted at major international conferences. (https://www.crt.org/research-updates) These aren't just academic wins; each publication and presentation represents new questions being explored, fresh hypotheses being tested, and steady progress in deepening our understanding of various cancers. Advances made possible by your generous support.

These successes are hard-earned, and they're a testament to the commitment of our researchers and to the belief you've placed in them and in Cancer Research & Treatment Fund. Thank you! Because when you donate to CR&T, your support provides the cornerstone of a future cure.

With gratitude,

### **Chad Feay**

Director of Administration & Development



n 2024, CR&T used 84 cents of every dollar received on research and educational programs — which means more money invested in improving patients' health and quality of life ... and ultimately, finding cures. We are proud that 100% of CR&T Board of Directors contributes financially to CR&T's mission. Below are ways you can consider supporting CR&T's mission. For more information, visit www.crt.org/ways-to-give

### · Donate online, by mail, or by phone

- Consider making this a recurring monthly gift
- Make this a tribute gift in honor or in memory of a loved one
- Check with your employer to see if they will match your contribution

### Donor Advised Funds (DAF)

- Contact your fund manager or financial institution to recommend a gift to CR&T.
- Multi-Year Pledge
- A multi-year pledge is a commitment from an individual or corporation to contribute a specified amount of support over multiple years
- Donors who make a multi-year pledge can choose a payment schedule that works best for them, offering both flexibility and convenience.
- By making a multi-year pledge, you're investing in the future of CR&T allowing us to plan long-term initiatives, expand our impact, and fulfill our mission more effectively.

#### Workplace Giving

- Many companies offer various giving programs that allow

you to deduct the amount you specify from your paycheck

 Check with your HR department-your company may match your donation!

### Gift of Securities

 Your stocks, bonds, or mutual funds can provide tax savings while helping to support CR&T's search for cures.

### · Wills, trusts, and annuities

- When you include CR&T in your estate plans, you create a lasting legacy that helps us build a cancer-free future.

### Event Participation

- Consider attending or donating to CR&T's Cancer Survivors Hall of Fame Dinner (www.crt.org/hall-of-fame-event)
- Consider sponsoring CR&T's Patient Symposium (www.crt.org/patient-symposium-on-mpns)

### Lastly, Spread the Word!

Share your donation experiences and the impact of your contributions with friends, family, and colleagues. By raising awareness and inspiring others to join your efforts, you amplify the collective impact of your gift and foster a culture of philanthropy within your community.



### **CR&T SUPPORTS PROSTATE CANCER AND HEALTH FAIR 2025**

CR&T'S mission includes funding research emphasizing the cause, prevention, treatment, and cure of all cancers. Since 2011, CR&T has been proud to co-sponsor the Annual Prostate Screening and Health Fair, held at First Presbyterian Church in Jamaica, Queens. Prostate cancer is the most commonly diagnosed non-skin cancer in America. If detected early, the disease has over a 90 percent survival rate. The 2025 event was held on Saturday May 3, where approximately 120 men were able to receive free prostate cancer screenings. New this year: a Mammogram bus on site which provided vital services to over 25 women; a great opportunity for women in the community to take care of their breast health.

The event is conducted by the church in collaboration with Douglas Scherr, MD, Professor of Urology and Clinical Director of Urologic Oncology at Weill Cornell Medicine, with nurses from First Presbyterian Church and technicians from Lab Corp. The health fair offers many other free tests for men and women, including HIV, blood pressure, diabetes, and cholesterol exams, as well as dental screening and nutritional counseling, serving over 500 community residents. Events like this one play a crucial role by providing preventive services to underserved communities.

For more information about First Presbyterian Church, the health fair, and its other community initiatives, visit www.crt.org/other-events.







2025 Prostate Cancer and Health Fair

### **MAB** and Board of Director News

Join us as we congratulate CR&T Medical Advisory Board Member John Leonard, MD as he announces his departure from Weill Cornell Medicine for a new leadership opportunity at NYU Langone.

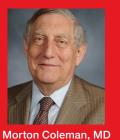
Dr. Leonard has been a crucial member of the Weill Cornell Medicine community for 35 years, as Senior



Associate Dean for Innovation and Initiatives, the Richard T. Silver Distinguished Professor of Hematology and Medical Oncology, and Professor of Medicine. He also served as executive vice chair in the Weill Department of Medicine and twice served as its Interim Chair. Dr. Leonard will no doubt be just as essential to NYU Langone going forward.

CR&T honored Dr. Leonard with its Lifetime Achievement Award at the 2023 Cancer Survivors Hall of Fame Dinner. We are pleased that Dr. Leonard has indicated his desire to remain on CR&T's Medical Advisory Board and are grateful for his continued passion, enthusiasm, and input.

Congratulations Dr. Leonard!



**LLM Congress Chair** 

"We started the Lymphoma." Leukemia & Myeloma Congress in 2000, and it has grown to be the most comprehensive conference on non-malignant and malignant lymphoid and related cellular disease conditions."

## SAVE THE DATE



October 14-17, 2025 · New York City

For more information, visit https://www.hmpglobalevents.com/llmcongress



### WEDNESDAY, **NOVEMBER 5, 2025**

14TH INTERNATIONAL PATIENT SYMPOSIUM ON **MYELOPROLIFERATIVE NEOPLASMS (MPNS)** 

Hosted by Cancer Research & Treatment Fund https://www.crt.org/patient-symposium-on-mpns

Belfer Research Building: Weill Cornell Medicine 413 East 69th Street • New York, NY 10021







17th International Congress Myeloproliferative Neoplasms November 6-7, 2025 = Brooklyn, New York

With over 400 hematologic oncology professionals expected to attend, the Congress promotes collaboration and knowledge exchange among specialists dedicated to advancing MPN research and treatment.

#### PROGRAM HIGHLIGHTS

- World-renowned speakers
- Engaging presentations
- Interactive discussions
- · Extensive networking opportunities
- · CME/CE-accredited education for physicians, nurse practitioners, PAs and nurses





https://MPNCongress2025.com

### Congress Organizer:



Melton Medical Education, LLC Email: info@meltonmeded.com Phone: 512-619-5534

SAVE



# **2025 CANCER SURVIVORS** HALL OF FAME DINNER

**THURSDAY, NOVEMBER 20, 2025** 

The Essex House • 160 Central Park South • New York, NY



**NICK NAPOLITANO CANCER SURVIVOR HONOREE** 



**KASIA MCCORMICK** RICHARD T. SILVER, MD HUMANITARIAN HONOREE

**GUEST ENTERTAINER** Tom Pesce, Magician

https://www.crt.org/hall-of-fame-event







### **Support Programs at Cancer Centers**

MPN Specialists at the Cancer Centers are experts who look beyond your blood cancer to provide care for the whole you through a diverse range of free services, including: one-on-one personal counseling, nutrition, patient education, social work, support groups and integrative health using yoga and meditation to help cancer patients feel better by reducing fatigue, nausea, pain and anxiety.

Cancer Survivorship Clinics provide services that help cancer survivors live well and help manage physical and emotional changes you may experience after your cancer treatment.

### Leukemia & Lymphoma Society (LLS)

The Leukemia & Lymphoma Society (https://lls.org) has a wealth of information, resources and support available to blood cancer patients and their caregivers. Speak one-on-one with an Information Specialist who can assist you through financial and social challenges, co-pay assistance, patient travel assistance, telephone/web patient programs and booklets, nutritional consultations, support groups and more. For a complete list of covered expenses, available funding, and a list of other helpful organizations visit their website.

### **Patient Assistance Programs**

Before you begin treatment, patients and caregivers should meet with an Oncology Nurse Navigator who helps provide support services, coordinates elements of care and helps you learn about additional cancer resources. See below for a partial listing of patient assistance programs for MPNs. For a list of other helpful organizations, go to Resources on the MPN Cancer Connection website. (https://mpncancerconnection.org/patient-resources)

### **Copay and Medication Assistance**

**CancerCare**-offers copay assistance for MPNs. https://www.cancercare.org/co\_payment\_fundings/myeloproliferative-neoplasms

**Good Days**—works directly with pharmacies and doctors to pay for patients' out-of-pocket expenses for medicines, including Pegasys and Jakafi. https://www.mygooddays.org

**IncyteCares**–provides support and copay assistance for eligible patients taking the Incyte medication Jakafi. https://www.incytecares.com

Patient Access Network Foundation–(PAN) offers help to underinsured people with life-threatening, chronic and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability. https://www.panfoundation.org

PharmaEssentia SOURCE—will help you get access to BESREMI. https://www.pharmaessentiasource.com/financial-assistance

**CTI Access**—is committed to helping patients, caregivers and healthcare professionals access VONJO (pacritinib). https://ctiaccess.com.

### **Financial Assistance**

**HealthWell Foundation**–provides financial assistance to eligible individuals to cover coinsurance, copayments, health care premiums and deductibles for certain medications and therapies. https://www.healthwellfoundation.orgs.

**NeedyMeds**–is a nationwide non-profit organization that has free information on medication and healthcare costs savings programs including prescription assistance programs and medical and dental clinics. https://www.needymeds.org

Patient Advocate Foundation – provides financial assistance to qualified patients assisting them with prescription drug co-payments their insurance requires relative to their diagnosis as well as arbitration, mediation, and negotiation services. https://www.patientadvocate.org

### **Travel and Airfare Assistance**

**Air Care Alliance**– (ACA) provides a listing of nonprofit organizations nationwide that fly patients to treatments at no charge. https://www.aircarealliance.org

Angel Flight Central–(AFC) is a volunteer non-profit organization whose mission is to "Serve people in need by arranging charitable flights for health care or other humanitarian purposes" throughout the Central U.S. https://angelflightcentral.org

Mercy Medical Angels—is ready to help patients in financial need and your caregiver with transportation on the ground and in the air to life changing, life-saving medical care. https://www.mercymedical.org

**Key Takeaway:** As a cancer patient with MPN, there are plenty of programs available to help ease your financial burden. **Be sure to reach out to a financial navigator at your cancer center for additional assistance.** 

Reprint courtesy of David Wallace, PV Reporter visit https://bit.ly/437zprN for the original article in full.

### **Additional Patient Assistance Programs:**

Aplastic Anemia and MDS International Foundation www.aamds.org/support/external-resources

**Bone Marrow & Cancer Foundation** www.bonemarrow.org/support-and-financial-aid/cancer-financial-assistance

### **National Organization for Rare Disorders (NORD)**

www.rarediseases.org/patient-assistance-programs/financial-assistance

New York Cancer Foundation www.nycancerfoundation.org

Susan G. Komen www.komen.org/support-resources/ financial-assistance

Travel to Hope https://traveltohope.org





# Cancer Research & Treatment Fund. Inc. (CR&T)

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### **ABOUT CR&T**

Since 1968, CR&T has funded the world's most promising physician-scientists, equipping them with the resources to advance the treatment of various types of blood cancers, including myeloproliferative neoplasms (MPNs), leukemia, non-Hodgkin's lymphoma, Hodgkin's disease and multiple myeloma, as well as other common cancers, such as breast and lung cancer.

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