

TELEMEDICINE SPECIALIZED CARE DIRECTORY

Myeloproliferative Neoplasm Edition



CONTENTS

- 01 About the MPN TelemEducation Resource Center
- 02 Utilizing Your MPN Telemedicine Toolbox
- 04 Connecting to Specialized Care
- 08 MPN Tools and Resources

This program is brought to you by Patient Empowerment Network. It is made possible through support from AbbVie, Incyte, and generous donations from people like you.



About the MPN TelemEducation Empowerment Resource Center



The **TelemEducation Empowerment Resource Center** works to significantly improve MPN patients' and caregivers' familiarity with remote access to healthcare, and thus increase quality of care regardless of geographical location.

This one-of-a-kind resource center is intended to educate the MPN community on the practical usage of telemedicine tools, to humanize patient and provider experiences.

Noticeably, telemedicine options of virtual visits with healthcare providers, access to patient portals, and virtual translation services have resulted in improved patient care. Patients who were previously too far away or could not get enough time off from work for in-person visits can now have virtual visits, and patients who have limited English language proficiency can now easily take advantage of translation services – all leading formerly underserved patients to better care.

Now that telemedicine has broader application, we now shift to how and why to keep telemedicine in your toolbox post-COVID. We also explore the digital health landscape and mobile-optimized tools for connecting to specialized cancer care.

"I think telemedicine is here to stay, and I think it's an important part of the care for patients with MPNs."

Kristen Pettit, MD





Utilizing Your MPN Telemedicine Toolbox

MPN Treatment Tools and Advancements

Expert: Kristen Pettit, MD



What Is Next Generation Sequencing for MPNs?

Expert: Kristen Pettit, MD



What Is Chronic Neutrophilic Leukemia?

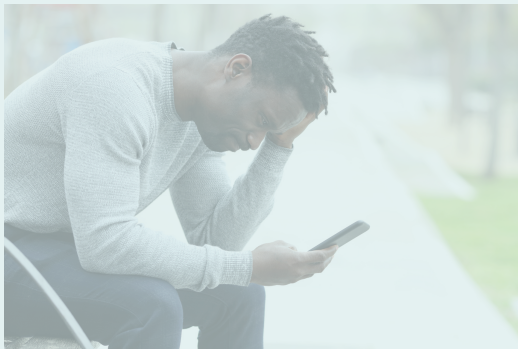
Expert: Kristen Pettit, MD



Should MPN Patients and Their Families Continue Telemedicine?

Expert: Kristen Pettit, MD





Utilizing Your MPN Telemedicine Toolbox

What Is the Role of Artificial Intelligence (AI) in Telemedicine for MPNs?

Expert: Kristen Pettit, MD



Understanding What ECG Monitoring Tools Mean for MPN Patients

Expert: Kristen Pettit, MD



Why Is Specialized Care Important for MPN Patients?

Expert: Kristen Pettit, MD



New Developments in MPN Care

Expert: Kristen Pettit, MD



Connecting to Specialized Care

If you are diagnosed with a myeloproliferative neoplasm (MPN), it's important to get your care from an experienced hematologist-oncologist who can work with you to create a treatment plan and coordinate your care throughout your entire treatment. Where possible, select a physician who specializes in MPNs.



Some questions to ask:

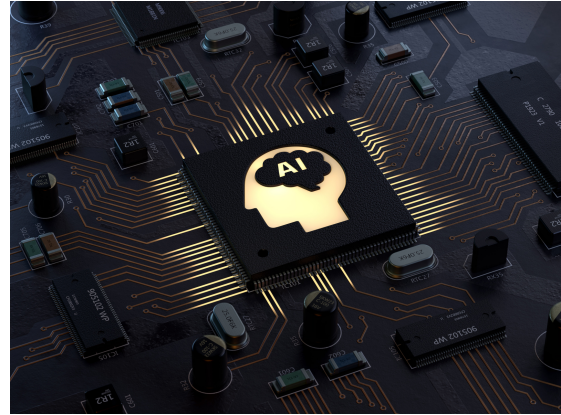
- Are they affiliated with a university or research hospital?
- Does their “bedside manner” align with your personality? Are they analytical? Compassionate?
- Do they seem interested in making you a partner in this process? Do they seem interested in what is important to you?
- What are the expected outcomes from my treatment?
- What is the prognosis of my disease?
- Am I eligible for a clinical trial?
- What support resources are available to me?



- Take your time
- Don't be afraid to shop around and get second or even third opinions.
- Be careful of random advice, e.g., “radiation is the best” or “eat this herb.”
- For accurate information, use data on reputable websites and those that your doctor recommends.
- After you have committed, trust is key, but continue to be your own advocate: ask questions, do research, and remain curious.

Artificial Intelligence (AI) and MPN Care

The use of artificial intelligence (AI) in telemedicine is ever-expanding. In telemedicine visits, AI can provide translations for non-native English speakers, more efficient analysis of imaging and other tests, use algorithms to better predict staffing levels for improved patient care, and much more.



What Artificial Intelligence (AI) Means for MPN Care

The increased use of artificial intelligence translates to improved care for MPN patients. Patient health can be monitored more frequently, more time can be spent with each patient, and tests can be evaluated more accurately through analysis by both providers and AI. These benefits will result in monitoring of treatment and symptoms more often for optimal patient care.

Future Developments for Artificial Intelligence (AI) in Telemedicine

As artificial intelligence continues to evolve, patients are apt to see even more treatment advancements and personalized care. Quality of life should improve as MPN specialists can spend more time learning about the latest MPN treatment advancements and to focus more on patient health outcomes.

Please remember to ask your healthcare team what may be right for you.

What Do Telegenetic Consultations Mean for MPN Patients?

Telegenetic consultations are those that can be carried out via telemedicine with genetic counselors.

With the rise of genetic mutations playing a factor in cancer care and treatment decisions, it's a natural progression for telegenetic consultations to become another option in the telemedicine tool box that protects patients from exposure to viruses and potential infections and saves them valuable time, energy, and travel costs.



What Telegenetic Consultations Mean for MPN Patients

With personalized medicine becoming an integral part of MPN patient care that analyzes genetic mutations like JAK2 mutations and MPL mutations, telegenetic consultations make sense as another part of the tools for MPN care. The future of MPN care looks brighter with these virtual care options as part of the equation.

Future Developments for Telegenetic Consultations

A form of tattoos called e-skins have now emerged as part of remote health monitoring. Used for detecting physical and electrical functions including heart, muscle, and brain activity, e-skins have shown reliability in monitoring tests even under body stress situations like sweating and while consuming spicy foods.

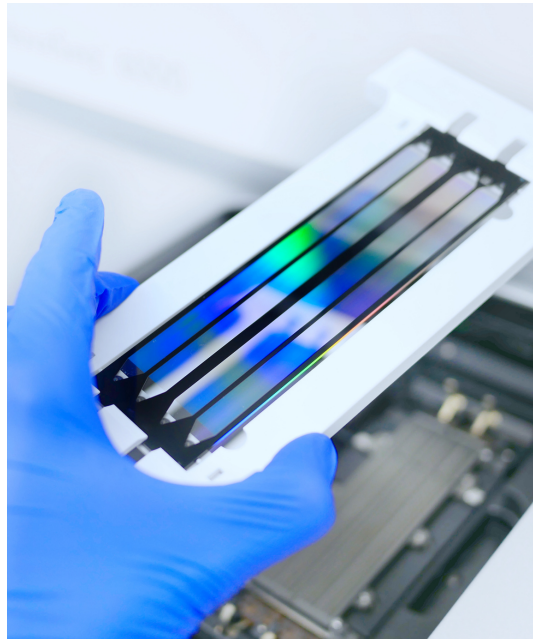
Please remember to ask your healthcare team what may be right for you.

Next-Generation Sequencing and MPNs

What Is the Role of Next-Generation Sequencing in MPNs?

Next-generation sequencing is a DNA analysis process that allows for sequencing of a portion of a patient's genome.

The process allows for processing of multiple DNA sequences in parallel. Next-generation sequencing also can identify hereditary cancer mutation carriers, cancer mutations, and other things.



What Next-Generation Sequencing Means for MPN Care

Next-generation sequencing is another medical advancement that helps improve MPN patient care. By identifying cancer mutations and hereditary cancer mutation carriers, next-generation sequencing helps oncologists to further refine targeted therapies and personalized medicine – leading to optimal patient care.

As more research continues in next-generation sequencing, it's possible that new genetic mutations will be discovered to further enhance quality of life with patient symptoms and treatment side effects.



"I think next-generation sequencing or NGS panels should be a part of the work-up for most patients with MPNs at the time of initial diagnosis, and probably again, at the time that there's any concern for disease progression in the future."

Kristen Pettit, MD

Resources to Find and Evaluate Doctors

Administrators in Medicine DocFinder

Information on licensing and disciplinary actions taken against doctors in 18 states; links to state medical boards of remaining states.

American Board of Medical Specialties (ABMS)

Includes a database to find doctors who are ABMS Member Board-Certified Specialists, a designation achieved through additional training and education.

American College of Surgeons

Information about finding surgeons who are board-certified as well as information about surgical specialties. Includes database of member surgeons.

American Medical Association DoctorFinder

Education, board certification, and hospital admitting privileges for doctors who belong to the AMA.

American Society of Clinical Oncology (ASCO) Cancer.Net

Oncologist-approved cancer information from the American Society of Clinical Oncology (ASCO) can be found on the site Cancer.Net. This site includes a “Find an Oncologist” tool with tips on choosing a doctor and a database of oncologists.

Medicare Physician and Other Healthcare Professional Directory

Provider profiles including specialties, practicing locations, and phone numbers. Other information may also include education, gender, residency, foreign languages spoken, and hospital affiliation.

PV Reporter

Vetted list of MPN specialists in the United States.

Source: Prostate Cancer Foundation

MPN Resources

National Cancer Institute (NCI) designated comprehensive centers and renowned treatment centers.

UAB Comprehensive Cancer Center

1824 Six Avenue South; Birmingham **Alabama**

Arizona Cancer Center

515 North Campbell Avenue; Tuscon **Arizona**

Chao Family Comprehensive Cancer Center

University of California Irvine

101 The City Drive

Building 56, Rt. 81. Room 216L; Orange, **California**

City of Hope Duarte

Comprehensive Cancer Center

1500 East Duarte Road; Duarte, **California**

Salk Institute Cancer Center

10010 North Torrey Pines Rd.

La Jolla, **California**

Sanford Burnham Prebys Medical Discovery Institute

10901 North Torrey Pines Rd

La Jolla, **California**

Stanford Cancer Institute

Stanford University

Lorry Lokey Stem Cell Building; 265 Campus Drive

Suite G2103; Palo Alto, **California**

UC Davis Comprehensive Cancer Center

University of California

Davis 4501 X Street Suite 3003; Sacramento, **California**

UC San Diego Moores Cancer Center

University of California at San Diego

3855 Health Sciences Drive; La Jolla, **California**

UCLA Jonsson Comprehensive Cancer Center

University of California

8-684 Factor Building, 10833 Le Conte Avenue

Los Angeles, **California**

UCSF Helen Diller Family

Comprehensive Cancer Center University of California at San Francisco
1450 3rd Street Box 0128; San Francisco, **California**

USC Norris Comprehensive Cancer Center

University of Southern California
1441 Eastlake Avenue; Los Angeles, **California**

University of Colorado Cancer Center

13001 East 17th Place
Aurora, **Colorado**

Yale Cancer Center

Yale University School of Medicine
333 Cedar St.; New Haven, **Connecticut**

Georgetown Lombardi Comprehensive Cancer Center

Georgetown University
3970 Reservoir Road, NW; Washington, **District of Columbia**

Moffit Cancer Center

12902 Magnolia Drive
Tampa, **Florida**

Winship Cancer Institute

Emory University
1365C Clifton Rd; Atlanta, **Georgia**

University of Hawaii Cancer Center

701 Italo St.
Honolulu, **Hawaii**

Robert H. Lurie Comprehensive Cancer Center

Northwestern University
303 East Superior Street; Chicago, **Illinois**

The University of Chicago

5841 South Maryland Avenue; Chicago, **Illinois**

Indiana University Melvin and Bren Simon Cancer Center
535 Barnhill Dr.
Indianapolis, **Indiana**

Purdue University Center for Cancer Research
Hansen Life Sciences Research Building
201 South University St.; West Lafayette, **Indiana**

Holden Comprehensive Cancer Center
University of Iowa
200 Hawkins Drive; Iowa City, **Iowa**

The University of Kansas Cancer Center
University of Kansas
3901 Rainbow Blvd; Kansas City, **Kansas**

Markey Cancer Center
University of Kentucky
800 Rose St.; Lexington, **Kentucky**

The Jackson Laboratory Cancer Center
600 Main St.
Bar Harbor, **Maine**

Sidney Kimmel Comprehensive Cancer Center
Johns Hopkins University
401 North Broadway; Baltimore, **Maryland**

University of Maryland Marlene and Stewart Greenbaum Comprehensive Cancer Center
University of Maryland
22 South Greene Street; Baltimore, **Maryland**

Dana-Farber/Harvard Cancer Center
450 Brookline Avenue
Boston, **Massachusetts**

David H. Koch Institute for Integrative Cancer Research at MIT
Massachusetts Institute of Technology
77 Massachusetts Ave; Cambridge, **Massachusetts**

The Barbara Ann Karmanos Cancer Institute
Wayne State University School of Medicine
4100 John R St.; Detroit, **Michigan**

University of Michigan Comprehensive Cancer Center
University of Michigan
1500 East Medical Center Drive; Ann Arbor, **Michigan**

Masonic Cancer Center
University of Minnesota
420 Delaware Street, S.E.; Minneapolis, **Minnesota**

Mayo Clinic Cancer Center
200 First Street SW
Rochester, **Minnesota**

Alvin J. Siteman Cancer Center
Washington University School of Medicine and Barnes-Jewish Hospital
660 South Euclid Avenue Campus; St Louis, **Missouri**

Fred and Pamela Buffett Cancer Center
University of Nebraska Medical Center
985950 Nebraska Medical Center; Omaha, **Nebraska**

Norris Cotton Cancer Center at Dartmouth
Dartmouth-Hitchcock Medical Center
One Medical Center Drive; Lebanon, **New Hampshire**

Rutgers Cancer Institute of New Jersey
Rutgers Biomedical and Health Sciences
195 Little Albany Street; New Brunswick, **New Jersey**

University of New Mexico Cancer Center
1201 Camino de Salud NE
Albuquerque, **New Mexico**

Albert Einstein Cancer Center
1300 Morris Park Avenue
Bronx, **New York**

The Barbara Ann Karmanos Cancer Institute
Wayne State University School of Medicine
4100 John R St.; Detroit, **Michigan**

Cold Spring Harbor Laboratory Cancer Center

1 Bungtown Road
Cold Springs Harbor, **New York**

Herbert Irving Comprehensive Cancer Center

Columbia University
1130 St Nicholas Avenue, Room 508; New York, **New York**

Memorial Sloan-Kettering Cancer Center

1275 York Avenue
New York, **New York**

Roswell Park Cancer Institute

Elm & Carlton Streets
Buffalo, **New York**

The Tisch Cancer Institute Mount Sinai

One Gustave L. Levy Place Icahn Building
New York, **New York**

Duke Cancer Institute

Duke University Medical Center
Box 2714 2424 Erwin Road; Durham, **North Carolina**

The Comprehensive Cancer Center of Wake Forest University

Medical Center Boulevard
Winston-Salem, **North Carolina**

UNC Lineberger Comprehensive Cancer Center

450 West Drive CB 7295
Chapel Hill, **North Carolina**

Case Comprehensive Cancer Center

Case Western Reserve University
11100 Euclid Avenue, Wearn 151; Cleveland, **Ohio**

The Ohio State University Comprehensive Cancer Center

James Cancer Hospital and Solove Research Institute
460 West 10th Avenue; Columbus, **Ohio**

Knight Cancer Institute

Oregon Health and Science University
3181 S.W. Sam Jackson Park Rd; Portland, **Oregon**

Abramson Cancer Center

University of Pennsylvania
3400 Spruce Street; Philadelphia, **Pennsylvania**

Fox Chase Cancer Center

333 Colttman Avenue
Philadelphia, **Pennsylvania**

Sidney Kimmel Cancer Center at Thomas Jefferson University

233 South 10th Street
Philadelphia, **Pennsylvania**

The Wistar Institute Cancer Center

3601 Spruce Street
Philadelphia, **Pennsylvania**

UPMC Hillman Cancer Center

5150 Centre Avenue
Pittsburgh, **Pennsylvania**

Hollings Cancer Center

Medical University of South Carolina
86 Jonathan Lucas Street; Charleston, **South Carolina**

St Jude Children's Research Hospital

262 Danny Thomas Place
Memphis, **Tennessee**

Vanderbilt-Ingram Cancer Center

691 Preston Research Building
Nashville, **Tennessee**

Cancer Therapy & Research Center

University of Texas Health Science Center
7979 Wurzbach Road; San Antonio, **Texas**

Dan L Duncan Comprehensive Cancer Center

Baylor College of Medicine
One Baylor Plaza; Houston, **Texas**

Harold C. Simmons Comprehensive Cancer Center

University of Texas Southwestern Medical Center
2201 Inwood Road; Dallas, Texas

The University of Texas MD Anderson Cancer Center

1515 Holcombe Boulevard, Unit 91
Houston, Texas

Huntsman Cancer Institute

University of Utah
2000 Circle of Hope; Salt Lake City, **Utah**

Massey Cancer Center

Virginia Commonwealth University
401 College Street; Richmond, **Virginia**

University of Virginia Cancer Center

6171 West Complex
Charlottesville, **Virginia**

Fred Hutchinson/University of Washington Cancer Consortium

1100 Fairview Ave N
Seattle, **Washington**

University of Wisconsin Carbone Cancer Center

1111 Highland Avenue, Rm. 7057
Madison, **Wisconsin**