



Raise Your Voice in Support of Myeloproliferative Neoplasm (MPN) Awareness

A toolkit for promoting unity, connection, and support



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The *Raise Your Voice in Support of Myeloproliferative Neoplasm (MPN) Awareness* Toolkit has been developed to help you take action to create awareness of MPNs during September when MPNs are being recognized as part of Blood Cancer Awareness Month. The introduction provides information about why awareness is important and how you can participate.

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■ INTRODUCTION ■

As a person affected by MPNs, you are likely to be all too aware of the challenges that living with a rare condition presents. You may wonder: Where are the bracelets and ribbons for MPNs? Where is the press coverage of what it is like to live with a rare blood cancer? What can I do to bring more attention to these conditions?

The answer is simple: Raise your voice. Unite with others who are affected by MPNs, and speak out so that your voices are heard and your stories are shared.

The *Raise Your Voice* Toolkit has been developed to help you take action to educate others about MPNs. Taking part in these activities will help to create supportive communities that unite organizations, health care providers, patients with MPNs, and caregivers.

■ How Do I Talk About MPNs? ■

Raising your voice means educating people who are not familiar with MPNs about what it is like to be affected by these conditions. A simple way to do so is to let people know that MPNs are a group of diseases in which the bone marrow—which produces the body's blood cells—develops and functions abnormally. MPN is a type of blood cancer that includes

- Polycythemia vera (PV)
- Essential thrombocythemia (ET)
- Myelofibrosis (MF)

It's also important to let people know that most people with MPNs have symptoms that affect their quality of life. There is hope for people living with these conditions, and that is why raising awareness is so important. But raising awareness about rare disorders like MPNs can be challenging because

- There are very few organizations dedicated to the condition
- Patients seeking help sometimes have trouble getting access to medical care
- Many doctors do not have experience diagnosing or treating MPNs. Outside of certain specialists who treat a small number of patients with MPNs, most community-based hematologists/oncologists provide care for very few patients with these orphan diseases in the course of their regular medical practice (and some have no experience with patients who have a MPN)

As a result, patients with MPNs tend to lack the information they need to understand their condition. They also may not receive the treatment or support services they need. That is why it is so important to raise your voice and support activities that raise the visibility of MPNs throughout your community.

■ What Can I Do? ■

Raise your voice! Become an activist. It's easy to do, and it can be fun. Bring together your family members, caregivers, children, or grandchildren, and work together to help promote awareness of MPNs in your community.

The resources in the *Raise Your Voice* Toolkit have been designed to give you the tools you need to host fun, practical activities that can help you, your family, and friends become activists in MPN care. The MPN Coalition—with the support of Incyte—a biopharmaceutical company that specializes in treatments for rare diseases—developed this Toolkit to provide you with ideas for how you can bring awareness to your local community.

■ When Can I Get Started? ■

Right now! September is Blood Cancer Awareness Month—a fitting time to start spreading the word about how people can make a difference in MPN care. The second Thursday of every September has been designated MPN Awareness Day. This year, MPN Awareness Day is September 12, 2013. But volunteers across the country are working to promote activities during the entire month of September. September is just the beginning, and MPN awareness activities are encouraged at any time and can and should be implemented all year long.

Start by reading through the resources in this Toolkit. They have been developed to help inspire you to get up, get out, and speak out. Share your voice with others through simple, fun activities that will help to

- Educate others in your community about MPNs
- Advocate for better care and support and more treatment options
- Connect with other patients diagnosed with a MPN and caregivers to form a MPN community

These resources are just a starting point. We hope that they will inspire you to think of ideas that may not be included here but that would work for your own MPN awareness activities.

■ How Can I Raise My Voice Through MPN Awareness Activities? ■

Efforts to raise MPN awareness can start locally, right in your own neighborhood, any time of the year. Consider hosting local activities to bring together your community, family, friends, and health care providers. These events are a way for you to help promote MPN disease education and connect with others.

Some suggestions for simple, fun activities that you can host in your community include

- Host a tailgate party, house party, or potluck. Invite your friends and family to hear stories about what it is like to live with a MPN. Hand out bracelets and ribbons to help promote awareness, and direct your guests to the MPN Coalition Web site to learn more
- Form a team for a *Light the Night* walk (for more information, see page 15)
- Hand out bracelets at local events, such as a Labor Day parade or a *Light the Night* walk
- Reach out to your local community center to share your experiences of living with a MPN. Community center staff are used to arranging local events, such as speaker engagements, on a host of topics. They can help you make arrangements to host a local event where you can speak to your friends and neighbors about your experience with MPNs
- Organize a local sporting event (eg, basketball or baseball game) to raise awareness of and fight MPNs. Again, your community or recreation center can be a helpful resource to help you organize these events at a local level

In addition to these live events, you can make use of social media to help form communities of people who have stories to share and support to offer. Some ideas include

- Creating a Facebook MPN support group. You can find simple step-by-step instructions at www.facebook.com/help/groups
- Arranging a Google hangout. You can find simple step-by-step instructions at www.google.com/+/learnmore
- Starting a Tumblr blog to share your story and connect with others living with MPNs. You can find simple step-by-step instructions at www.tumblr.com/tagged/ho%20to%20start20a%20blog

Using social media is also an opportunity to involve your children or grandchildren in promoting MPN awareness. Ask them to help you start an online group. Along the way, speak to them about why raising awareness for MPNs is so important. Share your personal stories. Before long, they will be raising their voices too.



How to Engage the Media in MPN Awareness Activities

■ HOW TO ENGAGE THE MEDIA IN MPN AWARENESS ACTIVITIES ■

One way that you can help to raise awareness is to share your personal story. Journalists often write public interest stories about how people cope with a certain condition. These stories help increase visibility among the public, patient, and professional communities.

By sharing your story, you can

- Advocate for better treatment and care
- Educate your family, friends, local community, and health care providers about MPNs
- Provide support and inspiration to other patients with MPNs and caregivers
- Create a close-knit community of patients with MPNs and caregivers

■ Sample templates included are a ■

- 1.1 Sample Public Service Announcement (PSA) for Local Radio or Television Stations
- 1.2 Sample Letter to the Editor
- 1.3 Sample MPN Awareness Press Release

The sample templates are written to help promote MPN Awareness in September 2013. **But remember, these types of activities can be hosted all year long, not just during September.** The templates are meant to be samples. You can customize them with the specific details of your event, any time you host one.

■ A step-by-step approach to engaging the media ■

Step 1: Identify media representatives from your local newspaper, radio, or television stations to approach about MPN awareness activities. Before sending any materials, identify the person most likely to broadcast your story to the public.

Step 2: Contact the person you have identified to have a preliminary discussion about

- Raising MPN awareness—what it is and why it is important
- Any newspaper, radio, and/or television station policies for broadcasting announcements to the public. You should also discuss
 - Who should receive the materials
 - What is the timeline for broadcasting the materials
 - How should you follow up and with whom
- Send a thank you note that briefly describes what you learned from the conversation

Step 3: Choose the best person to make the request of, and follow up as suggested by your contact. Share the template materials as you best see fit.

Step 4: Review the below sections to find out more about how to

- Engage the media
- Create a PSA
- Write a letter to the editor and press release

■ How to Engage the Media ■

What information should I convey to the media?

Reach out to the media to share your story. As someone living with a MPN or caring for someone with a MPN, you have an important story to tell. Many people, including the media, are not familiar with MPNs. It is important to let them know what MPNs are and that most patients with MPNs have symptoms that affect their quality of life.

The media are most interested in compelling stories about real people who have faced and overcome challenges and are on a mission to help others. Reporters may be interested in hearing your personal experience and perspectives on the following:

- *How were you diagnosed?* What are the symptoms of MPNs, and which ones did you have when you were diagnosed? How can someone find out if he or she has a MPN?
- *What is it like living with a rare disease like a MPN?* What is the nature of the illness? Which symptoms are most difficult to live with? What limitations does a MPN impose on a person's daily life?
- *How does a MPN affect a person's well-being?* How does the illness affect the patient, family, and caregiver? How does it impact his/her ability to work and social life?

How can I identify the media who might cover my story?

The reporters most likely to cover your story are those who report on health issues in your local newspapers, magazines, or television and radio stations. Call these media outlets, and ask for these reporters' names and contact information (phone numbers and e-mail addresses); keep a list for reference.

How can I get my story to my local media?

Call reporters and offer to make an appointment to meet with them. During the meeting be sure to

- Tell them about MPNs and explain what they are
- Talk about your personal experience with MPNs
- Share your MPN awareness activity press release (see page 13)

If reporters would prefer you send them materials rather than meeting with them in person (they usually do), you can do the following:

- E-mail them a press release describing your MPN awareness activity
- Follow up to make sure they got the information
- Explain your personal connection to this issue
- Offer to answer any questions they may have

What are some ways to make my story more attractive to the media?

There are a number of ways you can help encourage the media to pay attention to your story and to the activity you are hosting:

- Share your personal experiences of living with a MPN or caring for a loved one with a MPN with the media
- Host a MPN awareness event in your local community, and invite the media to cover the story

How can I use Facebook to publicize my story and my MPN awareness activity?

- Make sure you “friend” local thought leaders and media on Facebook or “like” the organization’s page
- Post links to relevant news stories about MPNs and any news stories that you successfully had published on your personal Facebook page
- On your personal Facebook page, regularly post updates on MPN awareness activities in your community
- Use the Voices of MPN™ logo as your profile picture

How can I use Twitter to publicize my story and my MPN awareness activity?

- Write and send a tweet (message) that is 140 characters or less on
 - Your experiences living with a MPN or caring for a loved one with a MPN
 - Local activities you are hosting or participating in to raise MPN awareness
 - Relevant news stories about MPNs or MPN awareness activities

- Use the hashtag #MPNAD
 - A hashtag marks key words or topics in a tweet
 - The hashtag will categorize tweets so they are easily found by others
 - When someone clicks on your hashtagged word they will see all other Tweets marked with that keyword
- Use the Voices of MPN logo as your picture

■ PSAs ■

What is a PSA?

Radio and television stations often broadcast free announcements to the community for a cause or charity. These announcements are called PSAs. You can submit a written PSA script to your local radio or television representative. These announcements are often 10 to 30 seconds long when read aloud.

How can I submit a PSA?

Different stations have different requirements for submitting PSAs. For example, some stations will allow you to call in your PSA by phone; others may require a written script. Call your local radio or television station or visit the station's Web site to find out about its PSA policies.

When will my PSA be broadcast?

Many radio and television stations may not track exactly when your PSA will be broadcast. But, if you ask, some stations will mail back a postcard to let you know the date and time when the PSA will be broadcast.

Can I submit images or videos as PSAs?

Some television stations will sometimes allow you to submit images or videos instead of a written PSA. Contact your local television station for details. When you submit a written PSA to your local television station about a MPN awareness activity, consider including an image of the Voices of MPN logo. The station will display the logo when broadcasting your PSA.

Another idea is to share the Voices of MPN logo with your local transportation authority and request a free display on buses and in subways and airports.

■ Letter to the Editor ■

What is a letter to the editor?

A letter to the editor is a piece that is written by readers of a newspaper, magazine, or other publication. The topic is something relevant to the publication's audience. Letters to the editor address many different topics, including

- Thoughts on local, state, national, and international current events
- Human interest commentary
- Responses to opinions and stories that have been previously published

How can I submit a letter to the editor?

To submit a letter to the editor, either call the publication of choice or visit its Web site. Publications will have a set of guidelines. Your letter must conform to these guidelines in order to be published. Guidelines generally include a maximum word count and require the author's contact information along with the letter. The editor of the publication will decide whether or not to publish the letter.

When will my letter to the editor be published?

If your letter is chosen, the publication date will depend on the publishing schedule of the publication you choose to target. Most publications run on a daily, weekly, bimonthly (twice a month), or quarterly schedule. When you contact the publication about guidelines, ask when an approved letter can expect to be published.

■ Press Releases ■

What is a press release?

A press release is a written announcement directed at members of the news media about something that an individual or group believes has news value. Sending a press release encourages journalists to write a news article on the subject. In this way, the subject of the press release gets more exposure. Press releases can announce a range of events related to business, charitable efforts, or community events.

How can I submit a press release?

Each publication and/or Web site has its own guidelines for submitting a press release. Contact the publication and/or Web site of choice for these guidelines. The editor of the publication and/or Web site will decide whether or not to publish a press release.

1.1 Sample Public Service Announcement (PSA) for Local Radio or Television Stations

This PSA has been written to promote MPN awareness. You can customize it to promote any MPN activity that you host at any time during the year.

Public Service Announcement

CONTACT: <Name, address, telephone number, and e-mail address>

USE THROUGH <DATE>

:30 (Indicates that announcement runs for 30 seconds)

As a person affected by myeloproliferative neoplasms (MPNs), you are likely to be all too aware of the challenges that living with a rare condition presents. You may wonder: What can I do to bring more attention to these conditions? The answer is simple: Raise your voice! Unite with others who are affected by MPNs and speak out so that your voices are heard and your stories are shared. Become an activist. It's easy to do, and it can be fun. Bring together your family members, caregivers, children, or grandchildren, and work together to help promote awareness of MPNs in your community. Join us in supporting MPN awareness this September. For more information on MPNs, visit www.VoicesofMPN.com.

1.2 Sample Letter to the Editor

This letter has been written to promote MPN awareness. You can customize it to promote any MPN activity that you host at any time during the year.

To the Editor

<DATE>

Re: September 12, 2013, is MPN Awareness Day

With all of the news about health care reform and policies, we can sometimes lose sight of individuals who are struggling day in and day out with health concerns. In particular, individuals with rare diseases—diseases whose names are not recognizable and which affect small numbers of patients—are often overlooked.

This September, raise your voice to support Myeloproliferative Neoplasm (MPN) awareness. Unite with others who are affected by MPNs, and speak out so that your voices are heard and your stories are shared. Become an activist. It's easy to do, and it can be fun. Bring together your family members, caregivers, children, or grandchildren, and work together to help promote awareness of MPNs in your community.

MPNs are a closely related group of conditions in which the bone marrow, which produces the body's blood cells, develops and functions abnormally. MPNs may also be classified as blood cancers. Three common MPNs are polycythemia vera (PV), essential thrombocythemia (ET), and myelofibrosis (MF). Most patients with MPNs have symptoms that affect their quality of life. MPNs are rare, and few health care providers have had the chance to diagnose or provide care for a patient with a MPN.

As a <person with> <caregiver for a person living with> <health care provider for patients with> a MPN, I hope that MPN awareness activities will help to improve the visibility of these diseases.

Sincerely,

<insert signature text>

1.3 Sample MPN Awareness Press Release

This press release has been written to promote MPN awareness. You can customize it to promote any MPN activity that you host at any time during the year.

Support Myeloproliferative Neoplasm (MPN) Awareness in September 2013

<DATE>

<contact>

For immediate release

September 12, 2013, marks the first MPN Awareness Day. Raise your voice to support MPN awareness during the entire month of September. Unite with others who are affected by MPNs, and speak out so that your voices are heard and your stories are shared. Become an activist. It's easy to do, and it can be fun. Bring together your family members, caregivers, children, or grandchildren, and work together to help promote awareness of MPNs in your community. MPNs are a closely related group of conditions in which the bone marrow, which produces the body's blood cells, develops and functions abnormally. MPNs may also be classified as blood cancers. Three common MPNs are polycythemia vera (PV), essential thrombocythemia (ET), and myelofibrosis (MF). Most patients with MPNs have symptoms that affect their quality of life. MPNs are rare, and few health care providers have had the chance to diagnose or provide care for a patient with a MPN. Accordingly, the time it takes for a diagnosis to be made is often a source of frustration for patients and families.

Volunteers across the country are working hard to promote MPN awareness during September. Please join us to help increase visibility of these diseases. For more information on MPNs, go to

- [CancerCare](http://www.cancercare.org/connect_workshops) (www.cancercare.org/connect_workshops)
- [Cancer Support Community](http://www.cancersupportcommunity.org/) (www.cancersupportcommunity.org/)
- [MPN Advocacy & Education International](http://www.mpnadvocacy.com/) (www.mpnadvocacy.com/)
- [The Leukemia & Lymphoma Society](http://www.lls.org/diseaseinformation/myeloproliferativediseases) (www.lls.org/diseaseinformation/myeloproliferativediseases)
- [The MPN Education Foundation](http://www.mpdinfo.org/) (www.mpdinfo.org/)
- [The MPN Research Foundation](http://www.mpnresearchfoundation.org/) (www.mpnresearchfoundation.org/)
- [The National Organization for Rare Disorders](http://www.rarediseases.org/rare-disease-information/rare-diseases/byID/244/viewAbstract) (www.rarediseases.org/rare-disease-information/rare-diseases/byID/244/viewAbstract)



How to Form a MPN Team for a *Light the Night* Walk

■ HOW TO FORM A MPN TEAM FOR A *LIGHT THE NIGHT* WALK ■

Each year, in communities all across the United States and Canada, teams of families, friends, coworkers, and local and national corporations come together for The Leukemia & Lymphoma Society's (LLS) *Light the Night* walks. These events bring help and hope to people battling blood cancers.

LLS provides information and resources for people with MPNs and partners with the MPN Research Foundation to help increase research for MPNs. That is why these walks are a natural fit for those interested in raising awareness of MPNs and contributing to a meaningful cause.

■ Step-by-step approach to organizing this event ■

Step 1 (team leader): Consider why you want to build a team. Creating a MPN team for a *Light the Night* walk will help achieve a number of goals, including

- Building support and awareness of MPNs among your community, family, health care providers, and friends
- Creating MPN awareness among the patients, caregivers, friends, health care providers, and others who participate in *Light the Night* walks
- Developing a network of people interested in learning more about MPNs

Step 2 (team leader): Create a team

- Find out when the event will be held in your area at the [Light the Night](http://www.lightthenight.org/) Web site (www.lightthenight.org/)
- Invite family, friends, neighbors, other patients, and caregivers to join your team
- [Register](http://www.lightthenight.org/ways/) your team (www.lightthenight.org/ways/)
- Sign up for [updates and helpful hints](http://www.lightthenight.org/ways/socialnetworking/) (www.lightthenight.org/ways/socialnetworking/)
- Post notices in your doctor's office, hospital, or clinic
- Ask local businesses to participate by walking with your team
- Create MPN awareness T-shirts for your team
- Send out a press release (see section 1.3, Sample MPN Awareness Press Release, for more information)



Policy Makers and Government Officials

■ HOW CAN POLICY MAKERS AND GOVERNMENT OFFICIALS HELP SUPPORT MPN AWARENESS? ■

One of the most common ways to bring attention to MPNs is for a mayor, governor, city council, or state legislature to declare MPN Awareness Day as an official day of observance through a proclamation. The second Thursday of every September has been designated MPN Awareness Day. This year, MPN Awareness Day is September 12.

Sample templates included are a

- 2.1 Letter of Request to Policy Maker
- 2.2 Sample MPN Awareness Day Proclamation

Remember, even though the steps and templates offered here are specific to MPN awareness for September, you can customize them to provide information to policy makers and government officials about MPNs and MPN Awareness activities.

Step-by-step approach for a proclamation

Step 1: Identify the appropriate policy maker(s) to approach about MPN awareness. It may be best to talk with more than 1 policy maker to potentially sponsor a proclamation. Before sending letters of request, identify the person best suited to bring messages to the policy maker(s):

- Policy makers include city councilors, mayors, governors, state and/or US representatives, and state and/or US senators. Visit the following Web site to find the policy makers that represent you: www.usa.gov/Contact/Elected.shtml
- For a mayor or governor's office: the aide(s) that work on health issues
- For a city council and state or US legislator: members of the committee(s) that deal with health issues

Step 2: Contact the person you have identified to have a preliminary discussion about

- MPN awareness—what it is and why it is important
- Any helpful guidance he or she may be able to offer on the appropriate steps to take to achieve your goal
 - Who should receive the request and materials
 - What is the timeline for decision making
 - How should you follow up and with whom
- Send a thank you note that briefly describes what you learned from the conversation

Step 3: Choose the best person to make the request and follow up as suggested by your contact. This may be a patient, caregiver, patient advocacy group leader, or local clinician who is a constituent of the politician.

Step 4: If your MPN awareness proclamation is granted by an elected official please consider asking them to send out a press release. (See section 1.3, Sample MPN Awareness Press Release, for more information).

2.1 Letter of Request to Policy Maker

<DATE>

<Title, First_Name, Last_Name>

<Address>

<Address_2>

<City, State, Zip>

Dear <Title> <Last_Name>,

As a concerned citizen of this country and <a person living with myeloproliferative neoplasms (MPNs), family member of or health care provider for a patient with a myeloproliferative neoplasm (MPN)>, I would like to request that you join with mayors, representatives, senators, and governors from across the United States to issue a proclamation declaring September 12, 2013, as “MPN Awareness Day” in <City>, <State>.

MPNs are a closely related group of conditions in which the bone marrow, which produces the body's blood cells, develops and functions abnormally. Three common MPNs are polycythemia vera (PV), essential thrombocythemia (ET), and myelofibrosis (MF). Most patients with MPNs have symptoms that affect their quality of life. MPNs are rare, and few health care providers have had the chance to diagnose or provide care for a patient with a MPN. Accordingly, the time it can take for a diagnosis to be made is a source of frustration for patients and families.

The 2013 theme for MPN awareness is to encourage those living with MPNs to use their voice and share their story to promote unity, connections, and support. I am enclosing a sample proclamation. If you agree to participate, <we, my hospital, my organization> will issue a press release to our local media and coordinate media coverage of a proclamation presentation.

I will call your office in a few days to further discuss the proclamation and answer any questions you may have. Thank you in advance for your consideration and approval of our request. Your help will be greatly appreciated by patients living with these disabling conditions.

Sincerely,

<insert signature text>

2.2 Sample MPN Awareness Day Proclamation

September 12, 2013, is National MPN Awareness Day

It shall be proclaimed:

WHEREAS myeloproliferative neoplasms (MPNs) are a closely related group of conditions in which the bone marrow, which produces the body's blood cells, develops and functions abnormally.¹

WHEREAS because MPNs are rare, few health care providers have had the chance to diagnose or provide care for a patient and, accordingly, the time it can take for a diagnosis to be made is a source of frustration for patients and families; and

WHEREAS patients and caregivers in <state or city> and around our country have joined together to promote MPN awareness and support—including improved education, diagnosis, research, and treatment; and

WHEREAS the community's focus on MPNs and their impact on patients' lives will help empower patients and increase hope for a better future for people with MPNs;

NOW, THEREFORE, I, <insert NAME>, do hereby recognize the needs of these chronically ill people and proclaim <date> as MPN Awareness Day in <insert text>, and urge all of our citizens to assist those individuals and families who live with these conditions on a daily basis.

¹ MPN Research Foundation. Learning about MPNs—PV, ET, PMF. <http://www.mpnresearchfoundation.org/Overview-Page>. Accessed July 2013.



Resources for Support

The following is a list of possible resources for support in launching some of the activities in this Toolkit. Some of the organizations have received funding from Incyte Corporation in support of educational or other activities.

MPN Coalition Members

Organization name	Contact information
<p>CancerCare</p> <p>CancerCare is the leading national organization committed to improving lives by providing professional services to help people manage the emotional and financial challenges of cancer. CancerCare's comprehensive network of services includes telephone, online, and in-person counseling and support groups; education; publications; resources; and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers and are completely free of charge.</p>	<p>275 Seventh Avenue New York, NY 10001 (800) 813-HOPE (4673) info@cancercares.org</p>
<p>Cancer Support Community (CSC)</p> <p>The CSC is an international nonprofit organization dedicated to providing support, education, and hope to people affected by cancer. Through a network of more than 50 affiliates, a vibrant online community, and a toll-free helpline, the CSC brings the highest quality cancer support to the millions of people touched by cancer so that no one has to face cancer alone.</p>	<p>1050 17th Street, NW Suite 500 Washington, DC 20036 (888) 793-9355 help@cancersupportcommunity.org</p>
<p>MPN Advocacy and Education International (MPN A&E)</p> <p>MPN A&E is dedicated to providing the knowledge, support, and resources to patients with MF, PV, and ET will need as they adjust to living with a MPN. This is done through educational symposia in several cities each year; Web site access; free webcasts of each program; collateral materials; and direction to people, resources, and other organizations that can help.</p>	<p>(517) 899-6889 abrazeau@mpnadvocacy.com</p>
<p>MPN Education Foundation</p> <p>A nonprofit organization run by volunteer patients with MPNs, the MPN Education Foundation was developed to advance research and knowledge about MPNs and improve quality of life and care of patients with MPNs.</p>	<p>www.mpninfo.org</p>

Organization name	Contact information
<p>MPN Research Foundation</p> <p>The mission of the MPN Research Foundation is to stimulate original research in pursuit of new treatments—and eventually a cure—for MPNs. The Foundation promotes collaboration in the scientific community to accelerate research and serves as a powerful advocacy group for patients and their families.</p>	<p>180 North Michigan Avenue Suite 1870 Chicago IL 60601 (312) 683-7249 mwoehrle@mpnresearchfoundation.org</p>
<p>National Organization for Rare Disorders (NORD)</p> <p>NORD is a unique federation of voluntary health organizations dedicated to helping people with rare “orphan” diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.</p>	<p>55 Kenosia Avenue Danbury, CT 06810 (203) 744-0100</p>
<p>The Leukemia & Lymphoma Society (LLS)</p> <p>As the world’s largest voluntary health agency dedicated to blood cancer, LLS funds lifesaving blood cancer research around the world and provides free information and support services. Its mission is to cure leukemia, lymphoma, Hodgkin’s disease and myeloma, and improve the quality of life of patients and their families.</p>	<p>1311 Mamaroneck Avenue, Suite 310 White Plains, NY 10605 (800) 955-4572 infocenter@lls.org</p>

■ Cancer Support Community (CSC), MPN Advocacy and Education International (MPN A&EI), MPN Research Foundation, and The Leukemia & Lymphoma Society (LLS) ■

Affiliates by State

The above organizations have local affiliates where you can also find help and support.

State	Affiliates
Alabama	<p>LLS</p> <ul style="list-style-type: none"> ● Birmingham: (205) 989-0098
Arizona	<p>CSC</p> <ul style="list-style-type: none"> ● Phoenix: The Wellness Community—Arizona, info@twccaz.org or (602) 712-1006 <p>LLS</p> <ul style="list-style-type: none"> ● Phoenix: Kathy VanMeter, kathyvanmeter@cox.net or (623) 326-2456
California	<p>CSC</p> <ul style="list-style-type: none"> ● Cathedral City: Gilda’s Club Desert Cities California, gcdinfo@dc.rr.com or (760) 770-5678 ● Los Angeles: Cancer Support Community Santa Monica (Benjamin Center), info@cancersupportcommunitybenjamincenter.org or (310) 314-2555 ● Pasadena: Cancer Support Community Pasadena, (626) 796-1083 ● Paso Robles: The Wellness Community California Central Coast, (805) 238-4411 ● Redondo Beach: Cancer Support Community Redondo Beach, info@wellnessandcancer.org or (310) 376-3550 ● Walnut Creek: Cancer Support Community San Francisco Bay Area, (925) 933-0107 ● Westlake Village: The Wellness Community Valley/Ventura, twcinfo@wellnesscommunityhope.org or (805) 379-4777 <p>LLS</p> <ul style="list-style-type: none"> ● Fresno: (559) 435-1482 ● Los Angeles: (310) 342-5800 ● Sacramento: (800) 410-8170 ● San Diego: (800) 215-1098 ● San Francisco: (415) 625-1100 ● San Jose: (408) 490-2663 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> ● Los Angeles: Ron Anderson, randerson@activetech.com ● San Diego: Antje Hjerpe, jahjerpe@sbcglobal.net ● San Francisco: Susan Klepper, Susanklepper@hotmail.com

State	Affiliates
Colorado	<p>LLS</p> <ul style="list-style-type: none"> • Denver: (720) 440-8620 <p>MPN/ MPN A&EI</p> <ul style="list-style-type: none"> • Denver: Mabel D. Peters, mabel.d.peters@kp.org
Connecticut	<p>CSC</p> <ul style="list-style-type: none"> • Branford: (203) 483-4227 <p>LLS</p> <ul style="list-style-type: none"> • Wilton: (203) 665-1400
Delaware	<p>CSC</p> <ul style="list-style-type: none"> • Dover: Kent County Office, (302) 734-0898 • Rehoboth Beach: Sussex County Office, (302) 645-9160 • Wilmington: Cancer Support Community Delaware, (302) 995-2850 <p>LLS</p> <ul style="list-style-type: none"> • Wilmington: (302) 661-0363
Florida	<p>CSC</p> <ul style="list-style-type: none"> • Fort Lauderdale: Gilda's Club South Florida, (954) 763-6776 • Miami: Cancer Support Community Greater Miami, (305) 668-5900 <p>LLS</p> <ul style="list-style-type: none"> • Hollywood: (954) 744-5300 • Orlando: (407) 896-8645 • Palm Beach Gardens: (561) 775-0930 • Tampa: (800) 436-6889
Georgia	<p>CSC</p> <ul style="list-style-type: none"> • Atlanta: Cancer Support Community Atlanta, (404) 843-1880 <p>LLS</p> <ul style="list-style-type: none"> • Atlanta: (404) 720-7879 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Atlanta: Bonnie Evans, kbemje@bellsouth.net or (404) 771-0010
Hawaii	<p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Oahu: Albert Loo, looa002@hawaii.rr.com
Idaho	<p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Boise: Susan Hill, jacksue@cableone.net

State	Affiliates
Illinois	<p>CSC</p> <ul style="list-style-type: none"> Chicago: Gilda’s Club Chicago, (312) 464-9900 <p>LLS</p> <ul style="list-style-type: none"> Chicago: (312) 463-0980 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> Chicago: Michelle Woehrle, mwoehrle@MPNResearchFoundation.org or (312) 683-7243
Indiana	<p>CSC</p> <ul style="list-style-type: none"> Evansville: Gilda’s Club Evansville, mmforston@gmail.com or (812) 402-8667 Indianapolis: Cancer Support Community Central Indiana, (317) 257-1505 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> Bloomington: Ellen, hankandellen@bluemarble.net
Iowa	<p>CSC</p> <ul style="list-style-type: none"> Davenport: Gilda’s Club Quad Cities, Claudia@gildasclub.org or (563) 326-7504 <p>LLS</p> <ul style="list-style-type: none"> Des Moines: (515) 270-5392
Kansas	<p>LLS</p> <ul style="list-style-type: none"> Shawnee Mission: (800) 256-1075 Wichita: (316) 266-4050
Kentucky	<p>CSC</p> <ul style="list-style-type: none"> Ft. Wright: Cancer Support Community–Greater Cincinnati/Northern Kentucky, (859) 331-5568 Louisville: Gilda’s Club Louisville, info@gildasclublouisville.org, (502) 583-2004 <p>LLS</p> <ul style="list-style-type: none"> Louisville: (502) 584-8490 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> Susan Kennedy, smkennedy0@gmail.com
Louisiana	<p>LLS</p> <ul style="list-style-type: none"> Metairie: (504) 837-0945
Maryland	<p>CSC</p> <ul style="list-style-type: none"> Salisbury: Cancer Support Community Delmarva, twcdmv@dmv.com or (410) 546-1200 <p>LLS</p> <ul style="list-style-type: none"> Owings Mills: (443) 471-1600

State	Affiliates
Massachusetts	<p>CSC</p> <ul style="list-style-type: none"> Norwell: Cancer Support Community Massachusetts South Shore, (781) 610-1490 <p>LLS</p> <ul style="list-style-type: none"> Natick: (508) 810-1300 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> Massachusetts & greater New England: silverlady3@gmail.com or mpdnewengland@gmail.com
Michigan	<p>CSC</p> <ul style="list-style-type: none"> Ann Arbor: Cancer Support Community Greater Ann Arbor, (734) 975-2500 Grand Rapids: Gilda's Club Grand Rapids, info@gildasclubgr.org or (616) 453-8300 Royal Oak: Gilda's Club Metro Detroit, (248) 577-0800 <p>LLS</p> <ul style="list-style-type: none"> Madison Heights: (248) 581-3900 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> Lansing: Ann Brazeau, abrazeau@MPNResearchFoundation.org
Minnesota	<p>CSC</p> <ul style="list-style-type: none"> Minneapolis: Gilda's Club Twin Cities, (612) 227-2147 <p>LLS</p> <ul style="list-style-type: none"> Golden Valley: (763) 852-3000
Missouri	<p>CSC</p> <ul style="list-style-type: none"> Kansas City: Gilda's Club Kansas City, (816) 531-5444 St. Louis: Cancer Support Community Greater St. Louis, info@cancersupportstl.org or (314) 238-2000 <p>LLS</p> <ul style="list-style-type: none"> St. Louis: (314) 590-2230
Montana	<p>CSC</p> <ul style="list-style-type: none"> Bozeman: Cancer Support Community Montana, (406) 582-1600
Nebraska	<p>LLS</p> <ul style="list-style-type: none"> Omaha: (402) 344-2242
Nevada	<p>LLS</p> <ul style="list-style-type: none"> Las Vegas: (702) 436-2396

State	Affiliates
New Jersey	<p>CSC</p> <ul style="list-style-type: none"> • Bedminster: Cancer Support Community Central New Jersey, (908) 658-5400 • Eatontown: Cancer Support Community Northern Jersey Shore, info@cscjerseyshore.org or (732) 578-9200 • Hackensack: Gilda's Club Northern New Jersey, info@gildasclubnj.com or (201) 457-1670 • Linwood: Gilda's Club South Jersey, info@gildasclubsouthjersey.org or (609) 926-2699
	<p>LLS</p> <ul style="list-style-type: none"> • Cranford: (908) 956-6600
New Mexico	<p>LLS</p> <ul style="list-style-type: none"> • Albuquerque: (505) 872-0141
	<p>MPN/MPN A&E</p> <ul style="list-style-type: none"> • Albuquerque: abq_mpn@yahoo.com
New York	<p>CSC</p> <ul style="list-style-type: none"> • Buffalo: Gilda's Club Western New York, gildas@gildasclubwny.org or (716) 332-5900 • New York: Gilda's Club New York City, info@gildasclubnyc.org or (212) 647-9700 • Rochester: Gilda's Club Rochester, info@gildasclubrochester.org or (585) 423-9700 • White Plains: Gilda's Club Westchester, info@gildasclubwestchester.org or (914) 644-8844
	<p>LLS</p> <ul style="list-style-type: none"> • Albany: (518) 438-3583 • Amherst: (716) 834-2578 • Hauppauge: (631) 370-7530 • New York: (212) 376-7093 • White Plains: (914) 949-0084 • White Plains: national office, (914) 949-5213
	<p>MPN/MPN A&E</p> <ul style="list-style-type: none"> • New York City: Susan Protter, sapla@aol.com or (212) 580-0115
North Carolina	<p>CSC</p> <ul style="list-style-type: none"> • Winterville: Cancer Support Community Eastern North Carolina, admin@cancersupportnc.org or (252) 364-1190
	<p>LLS</p> <ul style="list-style-type: none"> • Cary: (800) 936-9337
	<p>MPN/MPN A&E</p> <ul style="list-style-type: none"> • Janice Creed, jcreed@roadrunner.com

State	Affiliates
Ohio	<p>CSC</p> <ul style="list-style-type: none"> ● Cincinnati: Cancer Support Community Greater Cincinnati/Northern Kentucky, info@cancer-support.org or (513) 791-4060 ● Kettering: Cancer Support Community Western Ohio, (937) 223-4117 ● Powell: Cancer Support Community Central Ohio, (614) 791-9510 <p>LLS</p> <ul style="list-style-type: none"> ● Independence: (216) 264-5680 <p>MPN/MPN A&E</p> <ul style="list-style-type: none"> ● Akron/Cleveland: Jay Schmitt, ohiompd@sbcglobal.net ● Cincinnati: Rebecca Lubitz, rebeccalub@aol.com or (513) 793-3179
Oklahoma	<p>LLS</p> <ul style="list-style-type: none"> ● Oklahoma City: (405) 943-8888
Oregon	<p>LLS</p> <ul style="list-style-type: none"> ● Portland: (503) 245-9865
Pennsylvania	<p>CSC</p> <ul style="list-style-type: none"> ● Bethlehem: Cancer Support Community Greater Lehigh Valley, (610) 861-7555 ● Philadelphia: Cancer Support Community Philadelphia, (215) 879-7733 ● Pittsburgh: Gilda's Club Western Pennsylvania, (412) 338-1919 ● Warminster: Gilda's Club Delaware Valley, info@gildasclubdelval.org or (215) 441-3290 <p>LLS</p> <ul style="list-style-type: none"> ● Conshohocken: (484) 530-0832 ● Harrisburg: (717) 652-6520 ● Pittsburgh: (412) 395-2873 <p>MPN/MPN A&E</p> <ul style="list-style-type: none"> ● Philadelphia: Marie, mtomp57083@comcast.net
Rhode Island	<p>LLS</p> <ul style="list-style-type: none"> ● Cranston: (401) 943-1377
South Carolina	<p>LLS</p> <ul style="list-style-type: none"> ● Columbia: (800) 613-0550 <p>MPN/MPN A&E</p> <ul style="list-style-type: none"> ● Janice Creed, jcreed@roadrunner.com
Tennessee	<p>CSC</p> <ul style="list-style-type: none"> ● Knoxville: Cancer Support Community East Tennessee, (865) 546-4661 ● Nashville: Gilda's Club Nashville, info@gildasclubnashville.org or (615) 329-1124 <p>LLS</p> <ul style="list-style-type: none"> ● Nashville: (615) 331-2941

State	Affiliates
Texas	<p>CSC</p> <ul style="list-style-type: none"> • Austin: Cancer Support Community Central Texas, (512) 358-9876 • Dallas: Cancer Support Community North Texas, info@cancersupporttexas.org, (214) 219-8877 <p>LLS</p> <ul style="list-style-type: none"> • Dallas: (800) 800-6702 • Houston: (713) 680-8088 • San Antonio: (210) 998-5130 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Houston: Charlie Nielsen, charlienielson@aol.com
Utah	<p>LLS</p> <ul style="list-style-type: none"> • Murray: (801) 281-6618 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Salt Lake City: Rynda Brown, ryndabrown2006@yahoo.com
Virginia	<p>LLS</p> <ul style="list-style-type: none"> • Alexandria: (703) 399-2900 • Richmond: (800) 766-0797
Washington	<p>CSC</p> <ul style="list-style-type: none"> • Gilda's Club Seattle, info@gildasclubseattle.org or (206) 709-1400 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Seattle: Seattle MPD Yahoo Group
Wisconsin	<p>CSC</p> <ul style="list-style-type: none"> • Middleton: Gilda's Club Madison Wisconsin, (608) 828-8880 • Milwaukee: Gilda's Club Southeastern Wisconsin, (414) 962-8201 <p>MPN/MPN A&EI</p> <ul style="list-style-type: none"> • Racine: Karen Luba, klipluba@yahoo.com or (262) 552-7047