

International Myeloma Foundation Myeloma Action Month Proclamation Kit



Advocacy in Action

Improving Lives **Finding the Cure**

A Note on Proclamations

from Robin Roland Levy, Senior Director of Public Policy and Advocacy

MAM 2019



Dear Advocates,

Thank you for taking an interest in our yearly proclamation drive to raise awareness of myeloma. This is a first step in the process. Our goal is to draw attention to larger pieces of legislation, like oral parity bills at both the federal and state level and proposals that would create a Medicare Part D out-of-pocket max to help patients access the treatments they need. The relationships advocates form with their representatives while working on proclamations is a great way to move these important efforts forward in the future.

Because of your hard work to raise awareness, IMF Advocacy made record progress in advancing the priorities of myeloma patients in the 115th Congress (2017-2018). Your efforts resulted in myeloma researchers becoming eligible to receive Department of Defense research dollars and oral parity legislation (which would help patients access their oral chemotherapy drugs) reaching a record number of supporters!

With the start of the 116th (2019-2020) Congress, we began our efforts again. Our oral parity bills have been reintroduced and we have been working to gain support. The creation of a Medicare Part D cap and smoothing patient costs throughout the year have become a major issue that could become reality. As we push for passage of these important initiatives to help patients, we ask for your assistance. Please sign up for our advocacy newsletter and alerts. We will keep you updated as things progress and reach out to you as items come in, we need your help with.

With Appreciation,

A handwritten signature in black ink, appearing to read "R. R. Yew".



Table of Contents

A How-To-Guide for Proclamations	4
Finding Your Champion	6
Sample Cover Letter to Legislator	7
Sample Proclamation	9
Sample Press Release	11
MAM Media Guide	13
Tips for Sending an Effective Letter to the Editor	14
Sample Letter to the Editor	15



A How-To-Guide for Proclamations

How to Pass a Local Resolution/Proclamation for Myeloma Action Month

Having your hometown, county or state declare March as Myeloma Action Month is much simpler than you may think. It requires your town or county council to pass a non-binding resolution. We can walk you through this easy step-by step process:

Step by Step

1. Determine What Steps are Needed.

For many state level proclamations, simply asking for a proclamation is all that is required. If your state is one these, there is no reason not to ask!

2. Find a Champion in your Local Government to Introduce the Resolution.

If a resolution is required, you will need to have a government official to shepherd the resolution through the process. Ask other members in your support group if they know someone who could be helpful (council member, mayor, state legislator, etc). Or partner with a local hospital, wellness center or another cancer support group to ask if they have any allies at that level of government. If not, you may need to do some research.

3. Contact your Champion.

Once you identify the government official to lead the charge, find people who live in his/her district. Every governing body has their own path to getting measures passed. You will want to ask for the timeline in their governing body and if there are any other members you should speak to before a vote to ensure passage. Take any necessary actions promptly and report to the sponsor if necessary.

4. Day of the Hearing.

The Support Group Leader, or whoever has taken on leading this effort for your group, should make sure to sign up to speak during the public comment portion of the meeting. It is a good idea for the speaker to have a written statement. The speaker should briefly explain whom they represent (IMF and the name of the support group), why they support the resolution and the importance of it to the council members and community/state.



5. **Media.**

It is important to develop a list of media contacts to be used to publicize the proclamation once it is made. (*Refer to Media Tips*) Once you know the proclamation will be signed, make sure any and all MAM events are publicized in the media. Immediately send out a press release telling what was passed, what organization proposed it, who the primary sponsor was, and mention any other individuals who were instrumental in its passage. Include a photo of your group representatives with the public officials or you speaking to the group. Publicity is the way to make your community more aware of Multiple Myeloma. It will also show those who voted for the resolution you are grateful to them and you are taking action on the measure they spent time passing for you. We will provide you with a generic press release that you can customize and submit to local papers.



Finding Your Champion

If you want your city to offer a proclamation announcing March as Myeloma Month, chances are you need to contact your city council. Specifically, you will want to make this request to your councilman or councilwoman. So, how do you find your council member?

Typically, you might begin with an Internet search using “[your city name] city council. However, depending on the size of your town or city, you may need to find the name of your council member that represents your specific district. And there might be multiple district types, such as school or congressional, so you want to focus on which city council district you reside. Since your city district doesn’t necessarily line up with zip codes, you might need to input your mailing address or actually view district maps like I do in San Jose to make that final district number determination.

Finally, once you have your specific city council district number, it’s easy to look up your city council and determine which council member is yours by checking their district number. And why do you want to work with your specific council member? As a constituent, i.e. potential voter, of your council member, your request carries weight.

You will want to contact your council member by email, phone or in person and share your story of myeloma, along with proclamation and press release materials provided by the IMF. Let your member know that this is still an incurable cancer that he has probably never heard of. And let them know how many folks might be living in your city with Myeloma by taking your city’s population and multiplying by .00033 (determined by 100K folks living in US with MM divided by US pop of 300M = .00033). [For example, San Jose with a population of 1M residents has approximately 300 folks living with MM.]



Sample Cover Letter

Date:

Councilmember Name

Address

City

State and Zip

Dear Councilmember _____,

As a resident of the City and a Multiple Myeloma patient, I am requesting that the City of *[insert name of city]* proclaim the month of March 2020 as Myeloma Action Month. Multiple Myeloma is an incurable blood cancer of the bone marrow that affects more than 100,000 people in the United States, with an estimated 30,300 new cases diagnosed each year. More specifically, multiple myeloma is an uncontrolled growth of plasma cells in the bone marrow, which can lead to anemia, infections, bone lesions, vertebral compressions, osteoporosis, severe pain and kidney dysfunction.

[Insert personal story here]

With the support of the International Myeloma Foundation, I have been an active member of the *[insert name of your group]* Multiple Myeloma Support Group. This group brings together Myeloma patients, caregivers and family members to share experiences on treatments and outcomes. Our meetings are held on the *[insert day, time and location of meetings]*. Interestingly, through my association with the group, I have met many other residents within the *[insert name of city]* Metropolitan area who are also dealing with this disease. During this time, I have only met one person who had heard of myeloma prior to their diagnosis. This is the primary reason for us to build awareness of the disease, as early detection will help people live longer through many treatment options, including chemotherapy, radiation, stem cell transplantation and novel and emerging therapies.

I respectfully request your help in passing a resolution proclaiming March as Myeloma Action Month in the *[insert name of city]*. An example of the proclamation is below for your convenience. Should you have any questions, please contact me at *[insert your phone number]*.



Sincerely,

Name

Address

City, State, Zip



Sample Proclamation

PROCLAMATION

Expressing support for designation of March as “Multiple Myeloma Awareness Month”.

Whereas multiple myeloma (or myeloma) is a cancer of plasma cells in the bone marrow and is called “multiple” because it can occur at various sites in the body;

Whereas multiple myeloma causes a variety of adverse health effects, including a weakened immune system, anemia, kidney damage, and bone deterioration;

Whereas multiple myeloma is the second most common blood cancer worldwide;

Whereas multiple myeloma currently affects more than 100,000 people in the United States, with about 30,330 new cases diagnosed and 12,650 deaths from the disease in 2016 according to the National Cancer Institute’s Surveillance, Epidemiology, and End Results Program;

Whereas once predominantly found among those 65 and over, where it continues to be most frequently diagnosed, multiple myeloma is increasingly being identified in younger individuals including those in their 30s, 40s and 50s;

Whereas multiple myeloma is almost twice as likely to occur among African-Americans and is one of the leading causes of cancer deaths among African-Americans, with scientific understanding of the disparity remaining unknown;

Whereas the cause of multiple myeloma is not known, with robust research being performed in the United States and internationally into potential genetic, environmental, and other risk factors;

Whereas additional new drugs and therapies are in the research phase, with patient enrollment in clinical trials playing an important role in determining safe and effective treatments;



Whereas understanding and treatment of multiple myeloma has been greatly furthered by the role of advocacy initiatives promoting awareness, education, research, peer review, and collaboration and such efforts are to be highly commended;

Whereas greater awareness of multiple myeloma on the part of clinicians and the general public can lead to earlier detection and treatment, improving health outcomes and bringing comfort to patients and their families; and

Whereas March would be an appropriate month to designate as “Multiple Myeloma Awareness Month”: Now, therefore, be it

Resolved, That the (City/County/State) supports the designation of “Multiple Myeloma Awareness Month” to increase public knowledge of this disease and advance the vision of finding a cure for multiple myeloma.

NOW, THEREFORE, I, (governing body) DO HEREBY PROCLAIM THE MONTH OF MARCH 2020

MULTIPLE MYELOMA ACTION MONTH

IN (STATE/TOWN NAME) AND ENCOURAGE ALL RESIDENTS TO JOIN ME IN PARTICIPATING IN VOLUNTARY ACTIVITIES TO SUPPORT MYELOMA EDUCATION AND THE FUNDING OF RESEARCH PROGRAMS TO FIND A CURE.

IN TESTIMONY WHEREOF, I HAVE HEREUNTO SUBSCRIBED MY NAME AND CAUSED THE GREAT SEAL OF THE CITY/COUNTY OF SPECIFIC CITY OR COUNTY TO BE AFFIXED.



Sample Press Release

Contact: John Doe, Support Group Leader

Phone: XXX XXX XXXX

Email: jdoe@gmail.com

Mayor *[insert name of your mayor]* Declares March “Myeloma Action Month” *[Insert City, State, Date]* — *[insert City and Mayor’s name]* has proclaimed March 2020 “Myeloma Action Month”. According to the International Myeloma Foundation (IMF), Myeloma, also referred to as multiple myeloma, is an incurable cancer of cells in the bone marrow. Myeloma currently affects more than 100,000 people in the United States, with an estimated 30,330 new cases diagnosed in 2016. Myeloma is increasing in numbers and is becoming more common in younger patients, with possible links to environmental toxins.

“We appreciate Mayor *[name]*’s help in raising awareness of myeloma,” said *[insert your name]*, leader of the *[insert your support groups name]* Support Group. “This recognition is important to me because *[explain why this matters to you.]*”

[Insert your name], who lives in XXXX, was diagnosed in XXXX when he was XXX. “Our support group is a place where people with myeloma and their families can learn about the newest treatments available and gain support and education from those who have been living with the disease.” *[Insert a quote about your support group meetings]*

Myeloma Action Month is sponsored by the International Myeloma Foundation, the leader in global collaborative myeloma research. The IMF brings together the world’s leading myeloma experts through the International Myeloma Working Group (IMWG) and is charting a path to a cure through the foundation’s signature project, the Black Swan Research Initiative. ®

[Insert information for your support group meeting: Date, time, location, contact information, website]

XXX

ABOUT THE INTERNATIONAL MYELOMA FOUNDATION



The International Myeloma Foundation reaches more than 240,000 members in 120 countries worldwide. A 501 (c) 3 non-profit organization dedicated to improving the quality of life of myeloma patients and their families, the IMF focuses on four key areas: research, education, support, and advocacy. To date, the IMF has conducted more than 250 educational seminars worldwide, maintains a world-renowned hotline, and established the International Myeloma Working Group (IMWG), a collaborative research initiative focused on improving myeloma treatment options for patients. The IMF can be reached at (800) 452-CURE (2873). The global website is www.myeloma.org. Follow the IMF on Twitter at @IMFmyeloma and @IMFadvocacy.



Media Guide

March is right around the corner and that means Myeloma Action Month (MAM) is coming; you should consider how to maximize the impact of your MAM activities through media outreach. Here are a few ideas that could help get the word out about your event or tell your whole state about your accomplishments in raising awareness!

- **Contact your local newspaper or radio station**

Local papers love to publish stories about people in the area doing something for a good cause. Write a letter to the editor and share your story; they might just feature your event in the next issue. Radio stations also report on local happening and could become interested in your story. If you need help finding contacts, send us an email at advocacy@myeloma.org and we will be happy to assist!

- **Send out a notice on social media**

Do you use Twitter, Instagram, Vine, Facebook or any other social media sites? If so, take a moment and post a little something about your accomplishments. Blogs are also another great way to share with the world. Several patients have very successful blogs that have been featured in a number of newsletter and websites. Don't worry, it's not bragging!

- **Share your story with the IMF**

We love hearing about what our patient advocates are doing! Send us your story and we can feature it on our social media sites, the *Myeloma Minute*, *Myeloma Today* or in our monthly newsletter, the *Advocacy Update*. If you want to share with patient advocates directly, send us a message on [Facebook](#) and we will post for you!

For more ideas on amplifying your voice, or to get involved, contact the advocacy team at advocacy@myeloma.org.



Tips for Sending an Effective Letter to the Editor

The letters to the editor section are one of the most widely read sections of any newspaper or periodical. This section offers advocates a chance to reach a broad audience and provide readers with information and insights on unfamiliar issues that often inspire readers to take action.

1. **Be professional and identify yourself**

Letters should be typed or neatly handwritten and should follow the submission rules of the publication. Language should be polite, but persuasive. Use the sample letter as a guide but put your letter in your own words. Try to personalize your experience and frame your letter as a response to a recent article, editorial, or event covered by your newspaper. The publication will need to authenticate the letter, so sign your letter and provide contact information, including an address and daytime phone number. (Phone numbers will not be published; editors generally call authors to confirm the validity of the letter before publishing.)

2. **Keep it brief and get to the point Keep it short, to the point and concise.**

Keep your letter concise and to the point. Start with a compelling introductory sentence and follow with short and clear factual points. Introduce yourself and quickly describe your role and knowledge of the myeloma community. Check your newspaper's website for guidelines on word count; bear in mind that most newspapers will only accept letters of 150-200 words.

3. **End with a call to action**

Include your affiliation with IMF at the bottom of your letter if appropriate; however, be aware of how many times you mention the organization. Most newspapers will not submit letters that they find self-promotional. Ask readers to follow up. For example, urge them to join you and take action to empower the public and patients about myeloma.



Sample Letter to the Editor

Dear Editor,

March is Myeloma Action Month, and this year I am joining with the International Myeloma Foundation (IMF) to raise awareness about myeloma. Although myeloma is the second most common blood cancer, it can go undiagnosed until it begins to seriously damage health.

I am one of the more than 90,000 people in the United States living with myeloma in the United States. According to the National Cancer Institute's Surveillance, Epidemiology, and End Results Program, over 30,000 new cases of myeloma were diagnosed in 2016 and there were over 12,000 deaths from the disease.

I am joining with myeloma health care professionals, patient advocates, and caregivers to take action to empower the public about myeloma and empower patients and arm them with knowledge. Raising awareness about this rare disease can guide patients to ask their doctors to consider myeloma as a possible cause for their symptoms, leading to earlier diagnosis. Early diagnosis is a key aspect of achieving best outcomes for myeloma in 2020 and beyond.

For further information about myeloma you can contact the IMF InfoLine (infoline@myeloma.org) or the IMF website (www.myeloma.org). Information on how to take action on issues related to myeloma can be found at advocacy.myeloma.org or by emailing advocacy@myeloma.org.