



Together
we can.

Welcome to the
Melanoma Research
Foundation's 2022
Virtual Advocacy Days!



2022 Advocacy Days

March 7-11, 2022

AGENDA

March 7, 2022 (all times Eastern)

9:30 am	Welcome & Review of MRF 2022 Priorities	Kyleigh LiPira, MBA <i>CEO, Melanoma Research Foundation</i>
9:45 am	Recent Advances in Melanoma Care: How Increased Research Investment has Expanded Options for Patients	Laura Ferris, MD, PhD <i>Professor of Dermatology University of Pittsburgh, UPMC</i> Michael Postow, MD <i>Associate Attending Physician, Medical Oncology Memorial Sloan Kettering Cancer Center</i>
10:45 am	BREAK	
11:00 am	Congressional Town Hall: Updates on Skin Cancer Prevention and Melanoma Research & the Importance of Advocacy	The Honorable Carolyn B. Maloney, Representative from New York <i>NY-12</i>
11:30 am	Panel Discussion: Access Issues and Using Your Voice to Advocate	Richard Carvajal, MD <i>Associate Professor Columbia University Irving Cancer Center</i> Laurel Lindstrom Todd <i>Vice President, Public Policy & Advocacy Iovance Biotherapeutics</i> Kristin Nocco <i>MRF Advocate & Ocular Melanoma Survivor</i>
12:15 pm	BREAK	



12:30 pm	Legislator Roundtable: The Power of the Patient Advocacy Voice	<p>Adam Taliaferro, Esq. <i>Former New Jersey State Assemblyman & Strategic Alliance Lead, Bristol Myers Squibb</i></p> <p>State Rep. Steve Elkins <i>Minnesota District 49B & Melanoma Survivor</i></p> <p>State Rep. Hannah Kane <i>Massachusetts District 11 Worcester & Chair of Cancer Caucus</i></p> <p>State Assemblyman William Moen Jr <i>New Jersey District 5 & Deputy Majority Leader</i></p>
1:15 pm	Meeting Your Lawmaker 101: Tips and Tricks for a Successful Meeting	Liz Reilly & Kristin McJunkins <i>MRF Advocates & Melanoma Survivors</i>
2:00 pm	BREAK	
2:15 pm	Briefing: Congressionally Directed Medical Research Program (CDMRP), Melanoma Research Program (MRP)	Amie Bunker, PhD <i>Program Manager, Melanoma Research Program</i>
3:00 pm	Legislative Agenda: A Review of the MRF's Legislative Asks	Ed Long, PhD <i>Vice President, Van Scoyoc Associates</i>
3:45 pm	Closing Remarks	Kyleigh LiPira, MBA <i>CEO, Melanoma Research Foundation</i>
3:50 pm – 4:30 pm	State Caucuses: Breakout with advocates from your state to create an action plan for your Congressional Meetings. Practice your asks, share stories, and assign a state spokesperson.	ALL

March 8-11, 2022

9:00 am - 4:00 pm	Congressional Meetings with Advocates	
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www.melanoma.org
www.melanoma.org/how-to-help/advocate/

How to Conduct a Virtual Legislative Meeting

VIRTUAL VISITS

Without direct face-to-face interaction, it can be difficult to pick up on visual cues that advance the conversation in a natural way. In order to help coordinate your team meeting and minimize awkwardness in a virtual setting, be sure to enter every virtual meeting with assigned roles for each person. Adhering to these roles may help you stay organized and more effectively get your points across. However, don't get too caught up in your role – be flexible enough to change your role or even take on multiple roles in the middle of the meeting, if needed.

TEAM ROLES



Team Leader

- Ensures meeting flows as planned
- Keeps track of time
- Directs other participants



Impact Seller/Storyteller

- Can describe melanoma on a personal level
- Has anecdotes related to the ask
- Preferably a constituent of the legislator



Asker

- Clearly makes the ask
- Ensures there is no ambiguity regarding the ask



Scribe/Note-taker

- Takes notes on important ideas covered
- Sends notes to the team after the meeting for debrief
- Follows-up with thank you letters



Say Thanks: Team leader thanks the staffer or legislator for their time



Introductions: Team leader facilitates the introduction of the rest of the team to include *name, hometown, and relation to melanoma*



Preview the Ask: Team leader speaks of the ask in general terms *"We would like to discuss Defense-funded Melanoma Research"*



Describe Melanoma & Impact: Team leader directs the impact seller/storyteller to describe melanoma and the personal impact it has had on them



Restate the Ask: Asker makes a clear “yes or no” ask and clarifies any ambiguities of the staffer/legislator
“Will the Representative support \$35 million of medical research funding for melanoma?”



Conclude: Team leader once again thanks staffer or legislator for their time. Note-taker requests contact information and informs them that they will be in touch



Post-meeting: Note-taker sends key notes from the meeting to the rest of the team and sends thank you letters to the legislator and staff

Do's and Don'ts of Virtual Advocacy

- Keep yourself muted when you're not speaking
- Resolve technical difficulties prior to the meeting
- Make sure the staffer is on the call
- Make the staffer feel welcome
- Tell your story & relate it to the ask
- Clearly state the ask with no ambiguity, re-ask in yes-no format
- Request contact information to follow-up
- Thank the staffer for their time

DO...

- Have any background distractions (pets, young children, etc.)
- Show up late
- Be disrespectful
- Interrupt or talk over anyone
- Be unsure whether you are a constituent of the Congressperson
- Read off a personal device
- Ramble; stay concise and to the point
- Say anything negative

DON'T...



Sample Thank You Letter

The Honorable (Representative's Name)
U.S. House of Representatives
Washington, DC 20515

or

The Honorable (Senator's Name)
United States Senate
Washington, DC 20501

Dear Senator/Representative _____,

I would like to express my sincerest gratitude for the opportunity to meet with *[Insert staffer's name]* in a virtual meeting during the Melanoma Research Foundation's (MRF) Advocacy Days. I know your staff is very busy, particularly in the wake of a new administration, and I was pleased that we were able to meet and discuss issues impacting the melanoma community.

[Staffer's name] and I had a productive conversation about *[Include 1-2 sentences about each of the specific issues you discussed with this office including the bill and name of the bill where appropriate.]* I hope for your continued commitment to addressing key issues facing the melanoma patient community.

I look forward to continuing this relationship and to future meetings with both you and your dedicated staff. In the meantime, if I can be of any assistance, please do not hesitate to contact me.

Sincerely,

[Your name, title, and organization]

[Your Address]



MRF Federal Agenda Requests

Fiscal 2022 & 2023 Defense-funded Melanoma Research

- For Fiscal 2022 Defense Appropriations Conference
 - Support \$40 million for Defense-funded Melanoma Research Program (MRP)
 - House and Senate Fiscal 2022 Defense Appropriations bill include \$40 million for Defense-funded MRP
- Fiscal 2023 Defense-funded Melanoma Research
 - Support \$40 million for Defense-funded melanoma research in the Fiscal 2023 Department of Defense Appropriations bill
 - Ask your Representative to sign onto Congresswoman Carolyn Maloney's letter to House Defense Appropriations Subcommittee in support of \$40 million for Defense-funded melanoma research
 - Ask your Senator to contact Senate Defense Appropriations Subcommittee, in support of \$40 million for Defense-funded melanoma research in Fiscal 2023 Defense Appropriations bill

Fiscal 2022 & 2023 Funding for National Institutes of Health & National Cancer Institutes

- For Fiscal 2022 Labor, Health and Human Services (LHHS) Conference
 - Support House's \$3.5 billion increase for National Institute of Health's base funding
 - Support House's \$6.992 billion for the National Cancer Institute, a \$432 million increase
- For Fiscal 2023 LHHS bill
 - Support increased funding for NIH and NCI
 - Include Melanoma language under National Cancer Institute in the Committee Report accompanying the Fiscal 2022 Labor, Health and Human Services Appropriations bill

CDC Skin Cancer Prevention Activities

- Support \$5 million for the Centers for Disease Control and Prevention's Skin Cancer Prevention Activities in the Fiscal 2023 LHHS Appropriations bill
 - \$4 million for CDC's skin cancer prevention line in the House and Senate's Fiscal 2022 LHHS funding bills

Request that the Food and Drug Administration's Proposed Rule on Prohibiting Minors from Using Tanning Beds

- Ask your Member of Congress to write FDA requesting that the Agency finalize the proposed rule entitled "General and Plastic Surgery Devices: Restricted Sale, Distribution, And Use of Sunlamp Products," originally published by the FDA in the Federal Register on December 22, 2015 (80 Fed. Reg. 79493 et seq.)
- The FDA proposed rule prohibits minors under 18 from using tanning beds and requires adult tanning bed users to be informed about the serious health risks of indoor tanning through a risk acknowledgement citation, including notification of the risk of developing fatal melanoma and other skin cancers.



2022 Defense Appropriations Letter to Committee

Chairwoman Betty McCollum
House Appropriations Committee
Subcommittee on Defense
H-405 Capitol
Washington, DC 20515

Ranking Member Ken Calvert
House Appropriations Committee
Subcommittee on Defense
H-405 Capitol
Washington, DC 20515

Dear Chairwoman McCollum and Ranking Member Calvert:

We respectfully request that the Committee provide \$40 million for melanoma research in the Fiscal 2023 Defense Appropriations bill. This program is funded within the Defense Health account. The House and Senate's Fiscal 2022 Defense Appropriations bills both include \$40 million for the Defense-funded Melanoma Research Program.

Melanoma is a unique and major threat to our military community, who carry out their missions in environments of extreme solar radiation. Decades of studies from the time of WWII to the current generation of war fighters confirm the linkage of exposure to the development of deadly melanoma. Continued innovation in melanoma prevention, detection, and treatment is only possible with continued investment in high quality research.

A 2000 "Annals of Epidemiology" study comparing mortality among WWII veterans of the Pacific and European Theaters found that Pacific Theater Prisoner of War veterans had an estimated 3 times greater risk of dying from melanoma than veterans of the European Theater. The article concluded that these data are "consistent with the hypothesis that exposure to high levels of solar radiation in young adulthood is associated with a higher risk of melanoma mortality.

According to The Pulse, the online source for the Uniformed Services University, "melanoma is the most significant cancer to affect the active-duty military population." A Vanderbilt School of Medicine study--citing the following statistics--only 22 percent of military personnel were made aware of the risks of sun exposure; while 77 percent reported being exposed to bright sunlight for more than 4 hours a day, and only 27 percent having regular access to sunscreen. The study concluded that "the past decade of United States' combat missions, including operations in Iraq and Afghanistan, have occurred at a more equatorial latitude than the mean center of the United States population, increasing the potential for ultraviolet irradiance and the development of skin cancer."

Recent studies have borne out these conclusions. A study published in the Military Service Monthly Report found that in a 10-year surveillance period from 2005 to 2014, malignant melanoma was one of the most frequent diagnoses among male service members, the second most frequent cancer diagnosis among female service members. Another 2014 Military Medicine Study found that the overall incidence rate of melanoma in active-duty military personnel between 2000 and 2007 was 62 percent greater than among the generally populace during the same period.

Given the clear threat melanoma poses to our service members, and the volume of high-quality research proposals, we respectfully request that the Committee provide \$40 million for melanoma research in the Fiscal 2023 Defense Appropriations bill. Thank you for your consideration of this request.



Melanoma Specific Language Talking Points

National Institutes of Health National Cancer Institutes

Melanoma. Melanoma rates have been rapidly rising over the past 30 years with invasive melanoma the fifth most commonly diagnoses cancer in the U.S. As UV radiation is established as the primary carcinogen for melanoma, the Committee urges NCI to support research directed at mutagenesis and early detection and risk classification strategies. Prospective studies of gene expression profiling (GEP) in defined patient subsets are necessary to assess their utility in classifying prognosis and guide management of early-stage disease, similar to studies in breast cancer patients which now guide use of adjuvant therapy.

Although SEER data show decline in mortality with the advent of new categories of treatment, some patients with advanced melanoma do not respond to initial treatment and many of the responders have disease that recurs. The Committee encourages NCI to expand research on mechanisms of primary and secondary drug resistance and validation of novel (host, tumor, blood and imaging-based) biomarkers that allow selection of optimal therapy and prediction of immune-related toxicities. Basic and translational goals should be facilitated through development and use of ever-improving models of human melanoma, including continued expansion to include the rare subtypes.

Building on the success of adjuvant therapies and promising results of neoadjuvant therapies in early-stage disease, the Committee encourages NCI to continue research addressing tumor cell dormancy, recurrence, and metastases. The Committee encourages NCI to support multicenter trials that will determine whether shorter courses of therapy will decrease toxicity and costs while maintaining benefit, identify which patients should receive adjuvant therapy, explore the role of neoadjuvant therapy in stage II disease, and expand its use in combination therapy development.

The Committee encourages NCI to support research on novel targets, especially for rare subtypes (uveal, mucosal and acral melanoma), and to support development of registries in such populations. The Committee requests an update on these requests and a status of NCI-funded melanoma research in NCI's Fiscal 2024 Congressional Budget Justification.