

AGENDA

Sixth Annual **ASH Advocacy Leadership Institute** June 6-7, 2016 **ASH Headquarters Conference Center** 2021 L Street NW, 10th floor Washington, DC 20036

Objectives:

- Participants will gain an understanding of how the federal legislative and regulatory processes work;
- Participants will learn about ASH's position on key policy issues;
- Participants will learn how to become effective advocates for hematology and will demonstrate new skills during visits with their congressional delegation;
- Participants will learn how ASH is involved in policy development;
- Participants will learn what opportunities are available through ASH to get involved in advocacy and other Society activities.

Monday, June 6, 2016

8:30 a.m. **Breakfast Available**

9:00 a.m. **Welcome and Introductory Remarks**

Alan Lichtin, MD

Chair, 2016 ASH Advocacy Leadership Institute

Introductions

ASH Advocacy Leadership Institute Participants

Background Materials:

- 2016 ASH Advocacy Leadership Institute Participants
- **ASH Staff Participants**

Overview of Workshop Objectives

Alan Lichtin, MD

9:15 a.m. Get Involved in ASH: Overview of ASH Programs, Activities, and

Opportunities

Matthew Gertzog, MBA, CAE ASH Deputy Executive Director

Background Materials:

- About the Society
- ASH Standing and Scientific Committees and Nomination Information

9:30 a.m. How a Bill Becomes a Law... and What Comes After: An Overview of the Legislative Process and ASH Advocacy Priorities

Suzanne Leous, MPA

ASH Director of Government Relations and Practice

Ellen Riker

ASH Consultant

Senior Vice President, Cavarocchi Ruscio Dennis Associates

Background Materials:

- Legislative Process: How a Bill Becomes a Law
- Legislative Process: The Authorization and Appropriations Processes
- Policy Basics: Introduction to the Federal Budget Process
- The Federal Budget Process (in Theory)
- Chart: Federal Appropriations Process
- Status of Fiscal Year (FY) 2017 Appropriations
- Graphic: Percentage of Bills Enacted as Laws on the Decline
- Differences Between Legislation and Regulation

10:30 a.m. NIH Perspective: Outlook for Hematology Research Funding and Workforce

Cindy Roy, PhD

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

Background Materials:

- Speaker Bio: Cindy Roy, PhD
- Hematology Research at NIDDK

11:30 a.m. ASH Efforts Related to Sickle Cell Disease and Trait

Stephanie Kaplan

ASH Senior Manager of Government Relations and Public Health

Background Materials:

Overview of ASH Efforts Related to Sickle Cell Disease and Trait

12:30 p.m. LUNCH

1:15 p.m. Group Photo

1:30 p.m. Overview of Federal Sickle Cell Disease Issues and Programs

Mary Hulihan, DrPH, MPH

Centers for Disease Control and Prevention (CDC)

Background Materials:

• Speaker Bio: Mary Hulihan, DrPH, MPH

2:30 p.m. Congressional Staff Perspective: What It's Really Like to Work on Capitol Hill and Why Advocacy Matters

Congressional Staff TBD

LaTasha Lee, PhD, MPH

ASH Manager of Sickle Cell Disease Policy and Programs

Previous Fellow in Offices of Representative Alcee Hastings (D-FL) and Senator Sherrod Brown (D-OH)

3:15 p.m. ASH Congressional Fellowship

Suzanne Leous, MPA

3:30 p.m. Tools for Capitol Hill Visits

Suzanne Leous, MPA

Ellen Riker

Tracy Roades

ASH Legislative Advocacy Manager

Background Materials:

- General Tips for Capitol Hill Visits
- Map of Capitol Hill
- Review of Issues, Fact Sheets, and Talking Points
 - o FY 2017 NIH Funding Fact Sheet
 - Sickle Cell Disease Fact Sheet
 - "Dear Colleague" Letter on CMMI Sickle Cell Disease Demonstration Program
 - o Capitol Hill Visit Talking Points

4:00 p.m. Role of ASH Communications in Getting the Advocacy Message Out

Amanda Szabo

ASH Communications Manager

Stephen Fitzmaurice

ASH Communications Specialist

Background Materials:

• Best Practices for Social Media Advocacy on Capitol Hill

4:15 p.m. Prep for Capitol Hill Visits

Role-Playing for Capitol Hill Visits

• Hill Day Group Break-Out

5:00 p.m. Adjourn

Additional Resources For Your Information:

- Chart: Overview of the Government of the United States
- Frequently Asked Questions About the Federal Government
- Physicians in the 114th Congress
- Additional Online Resources

Tuesday, June 7, 2016

7:30 a.m. Breakfast Available

8:00 a.m. Capitol Hill Visits/Strategy Review

 Overview, Logistics, and Schedule ASH Staff

8:15 a.m. Travel to Capitol Hill

9:30 a.m. – Congressional Visits

4:00 p.m. Each participant will visit his/her Representative and Senators as scheduled

and will leave ASH fact sheets with the Member of Congress or staff

person.

5:00 p.m. Departure

Follow-Up:

- Each participant will participate in an <u>ASH advocacy campaign</u> and will successfully encourage at least two colleagues to participate.
- Participants should plan to attend the Grassroots Network Lunch on Saturday, December 3, 2016 at the 58th ASH Annual Meeting and Exposition in San Diego, CA, where they will be recognized for their participation in the ASH Advocacy Leadership Institute.