

IDF Virtual State Advocacy Workshop

Ohio





MISSION STATEMENT

The Immune Deficiency Foundation improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education, and research.

ABOUT PRIMARY IMMUNODEFICIENCY (PI)

Primary immunodeficiencies (PIs) **include more than 400 types of rare, chronic disorders** in which part of the body's immune system functions improperly because of genetic or intrinsic defects. Fortunately, most people with PI can live healthy and productive lives if they receive lifelong immunoglobulin (Ig) replacement therapy to replace the antibodies the body is unable to sufficiently produce.



250,000 Diagnosed in the U.S. but thousands more go undetected

Individuals affected by PI often find it difficult to receive proper diagnosis, treatment, and specialized healthcare. They experience difficulties financing healthcare, finding educational materials, and locating others who share their experiences.

Housekeeping

- Attendees will be muted throughout the presentation, until sent to breakout rooms.
- To see the full slides, you can adjust the settings on the speaker view panel and select "side-by-side."
- To ask a question, please use the Chat box on the bar across the bottom of your screen. We will answer as many questions as we can in the order we receive them.
- Say Hello in the Chat box! Please say your name and what state you are from.

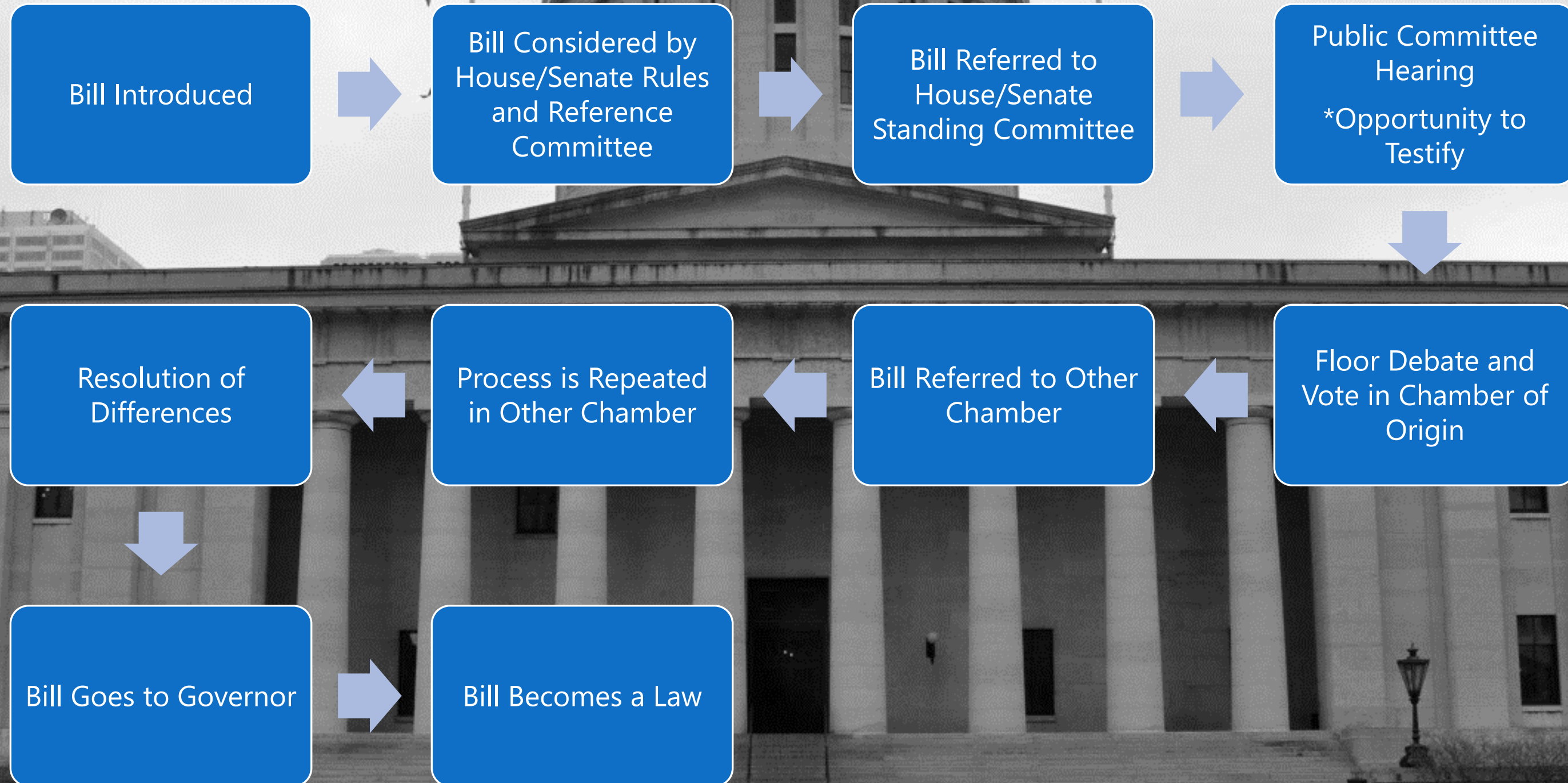


Influencing Policy in Your State

Ohio State Legislature

- Bicameral body consisting of two houses: Senate and House
 - 99 members of the Ohio House of Representatives
 - 33 members of the Ohio Senate
- Full-time legislature
- The Legislature convenes on the first Monday of January and the regular session usually takes place until the last week of December.

The Legislative Process in Ohio



Governor

Mike DeWine (R)

The governor is the head of the executive branch in Ohio. All bills passed by the Ohio State Legislature go to the governor, who can sign the bill into law, allow it to become law without his or her signature, or veto it.



Speaker of the House

Robert Cupp (R)

The Speaker is the highest ranking officer of the House, and is elected by the House Members usually at the beginning of each two-year legislative session. The Speaker is charged with the overall management and supervision of the House. She or he appoints members to all committees and subcommittees of the House, allocates funds, staffing, and other resources for the effective operation of the House, and establishes committee schedules.



Senate President

Larry Obhof (R)

The President of the Senate is the leader of the chamber. He or she is elected by the Members at the beginning of each Session. The President is the presiding officer on the Floor, overseeing the appointment of committee members, progress of legislation through the Senate, and overall direction of policy. He or she is also the political leader of the majority party.





Advocacy Issue in Ohio

Barrier: Burdensome Plasma Center Regulations

- It takes approximately 130 plasma donations to produce enough immunoglobulin (Ig) to treat a single adult with PI for one year. As a result, the PI community relies on an adequate number of plasma donors and donation centers around the country.
- While Ohio currently has plasma donation centers across the state, burdensome regulations placed on these centers limit their efficiency.
- These burdens hinder the productivity of healthcare professionals during plasma collection in Ohio, and in turn negatively impact the success of plasma centers themselves.
- Raising awareness about plasma donation and urging legislators to introduce and pass legislation to remove these burdens is essential to the wellbeing of the PI community.

Legislative Asks to Address this Barrier

Raise Awareness for the Importance of Plasma Donation

Remove Burdensome Regulations on Plasma Donation Centers

Raising Awareness About Plasma Donation

- Plasma donation is important to the PI community because our treatment, immunoglobulin (Ig), is made with the donated plasma.
- It takes approximately 130 plasma donations to produce enough Ig to treat a single adult with PI for one year.
- Therefore, the PI community relies on an adequate number of efficient plasma donor centers in the state and the country.
- Touch on the importance of Ig to you personally

Removing Burdensome Regulations

- Presently, Ohio's regulations for plasma donation centers are out of sync with those present in most of the 44 states across the country where plasma is donated.
- Current Ohio Law strictly limits which licensed healthcare workers can supervise plasmapheresis. This regulation effectively prevents professionals from being utilized to the highest level of their job skills, resulting in less efficient plasma collection.
- Synchronizing Ohio's laws with those in much of the rest of the country will help ensure the existence and efficiency of plasma donor centers in the state.

Legislation to Address Burdensome Plasma Center Regulations in Ohio

- It is vital to the PI community that the state of Ohio continues to have an adequate number of plasma donation centers in the state and that these centers are efficient and safe.
- Ohio officials can support this need by introducing and passing legislation that removes the burdensome regulations on plasma donation in the state, and ensuring that state guidelines are in sync with federal law.
- Eliminating such burdens was attempted this spring at the dawn of the COVID-19 pandemic, but has been unsuccessful.
- The current health crisis has caused a tremendous strain on the healthcare workforce, presenting an even greater need for officials to address this unreasonable regulation.



Effective Advocacy

Your Voice Matters

- You have tools that lobbyist don't - **real personal stories**
- People with PI and their families are the most effective at demonstrating how policies impact them
- Just by reaching out to them, legislators/staff can see that you and people like you have value with concerns to be addressed - **you cannot be ignored**
- Personal connections help members consider issues they may not have been inclined to support
- As a constituent and voter, legislators have a vested interest in addressing your concerns

Advocating for People with Primary Immunodeficiency (PI)

- Share your stories and experiences with policy makers
- Testify at hearings
- Work with other patient organizations on health access issues
- Mobilize other members of the PI community
- Respond to Action Alerts
- Email, write, and phone officials and urge leaders to take actions on issues affecting the PI community

How to Schedule A Virtual Legislative Visit

- Call or email the legislative office requesting a telephone or video conference. You can find your state representatives by visiting primaryimmune.org/current-action-alerts and using the "Find Officials" tool.
- Place your ask directly in the subject line of the email
- Make sure to explain who you are and why you are seeking an audience with your legislator
- Prior to the meeting, provide staff with fact-sheets, links, and/or any additional supporting documents

Virtual Meeting Pointers

- Prior to the call, make sure that your cellphone or laptop is in working order
- Make sure you are in a quiet location
- Turn off all other electronics (cellphones, television...)
- Avoid multitasking and stay 100% focused on the task at hand
- Be courteous and speak clearly into the phone or laptop
- Do not let the meeting stray
- Present the facts in a short and concise manner. It is okay to be brief.
- State your position and what you are asking the legislator to do
- Don't forget to say thank you!

Talking About Life with PI

- People with PI have improperly functioning immune systems and are highly vulnerable to recurrent and severe infections that often won't clear up
- Lifelong, plasma based, immunoglobulin (Ig) therapy, infused subcutaneously (SCIG) or intravenously (IVIG), allows people with PI to live healthy, productive lives
- Ig therapy is made from donated plasma and supplies the antibodies the body is unable to sufficiently produce itself
- Full access to affordable treatments using the method of administration and site of care most appropriate for each individual is a priority for IDF

Telling Your Story Virtually



- Use your own, authentic voice
- Share clean, logical arguments
- Make a solid, persuasive case
- Tell a true story and use personal examples
- Ask for the outcome you want
- Thank them for their time

Your Elevator Pitch

- Introduce yourself
- Tell your story
- Explain the challenge and build the tension
- Paint a picture and add details
- Describe outcome
- Share materials with back-up factual information
- Conclude – May be positive or sad but should inspire action
- Wrap it up and make the “Ask”
- Address the public or greater good
- Thank the listener



The Follow Up

- After the meeting, make sure to send a follow-up email thanking the person(s) you met with for their time and reaffirming the legislative ask
- Provide the legislator and their staff with pertinent materials (talking-points, fact sheets, links) as a courtesy
- Report your meeting with IDF staff for continuity

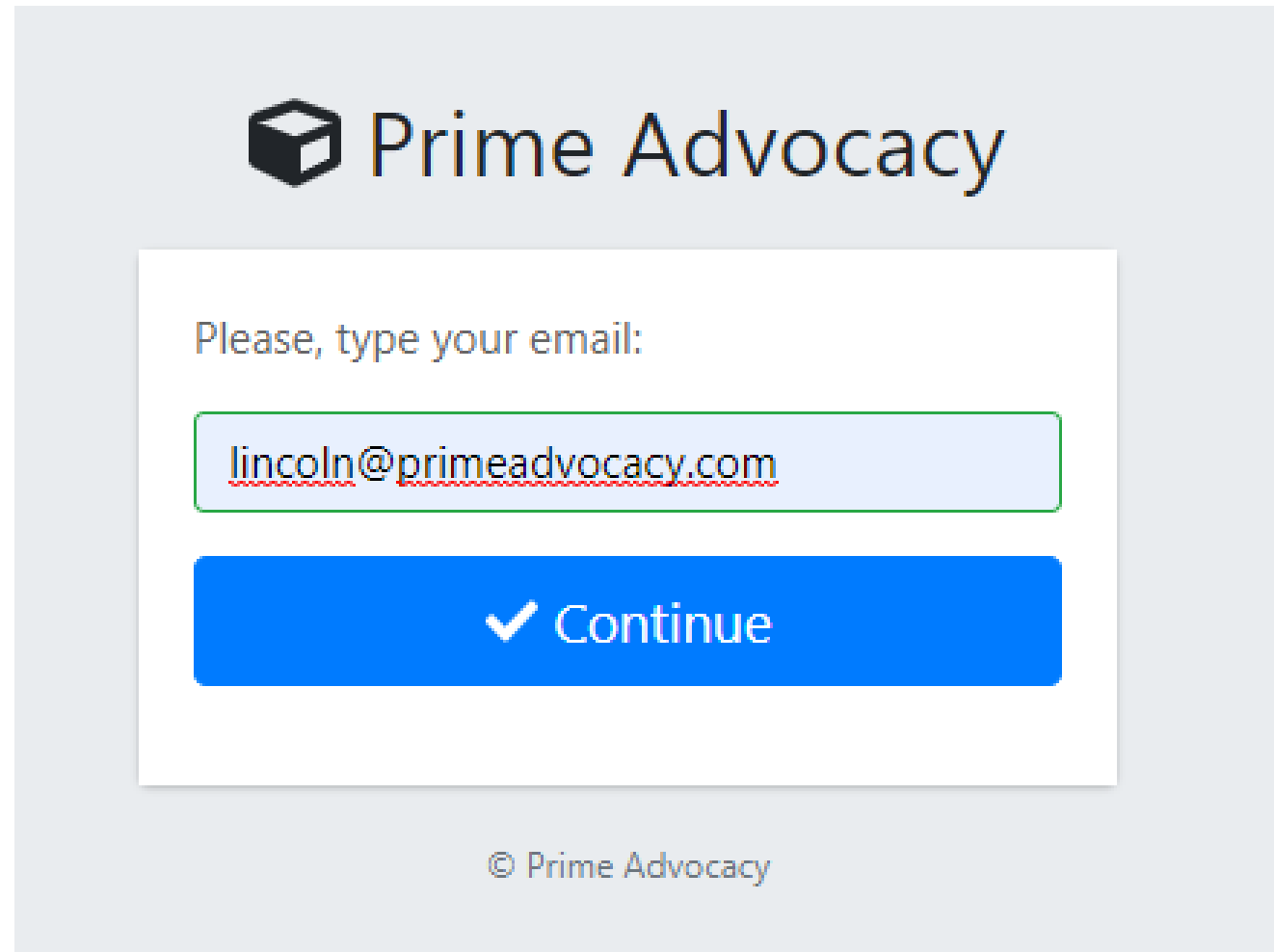


Breakout Rooms to Practice



Day of Action

Schedule and Logistics Overview



The image shows a login interface for Prime Advocacy. At the top, there is a Prime Advocacy logo. Below it, a text prompt says "Please, type your email:". Underneath the prompt is a text input field containing the email address "lincoln@primeadvocacy.com". Below the input field is a blue button with a white checkmark icon and the text "Continue". At the bottom of the interface, there is a copyright notice: "© Prime Advocacy".

Prime Advocacy

Please, type your email:

lincoln@primeadvocacy.com

✓ Continue

© Prime Advocacy

- Use your laptop, desktop, or tablet and pull up your web browser
- Log into your schedule at clients.primeadvocacy.com/attendee/login with **your** email address

Schedule and Logistics Overview

 Confirmed

- The **Status** of each meeting is in the upper right hand corner (color coded)

Time	10:55 AM
Office Of	Senator David Perdue
Meeting With	Legislative Correspondent: Kevin Gannon
Location	Dial-in: 1-253-215-8782; Access Code: 938-568-0666#
Party	R
State	Georgia
District	
Team Lead	Meryl Uganda
Special Notes	
Talking Points	<ul style="list-style-type: none"> - REMINDER: All meeting times listed are Eastern Time - REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through - REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation - Talking Points and Leave Behind Material (Click here) - Advocacy Telephone Script (Click here) - Advocacy 101 Agenda (Click here) - Scheduling or technical support? (Phone number listed here soon)

Schedule and Logistics Overview

		● Confirmed
Time	10:55 AM	
Office Of	Senator David Perdue	
Meeting With	Legislative Correspondent: Kevin Gannon	
Location	Dial-in: 1-253-215-8782; Access Code: 938-568-0666#	
Party	R	
State	Georgia	
District		
Team Lead	Meryl Uganda	
Special Notes		
Talking Points	<ul style="list-style-type: none">- REMINDER: All meeting times listed are Eastern Time- REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through- REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation <ul style="list-style-type: none">- Talking Points and Leave Behind Material (Click here)- Advocacy Telephone Script (Click here)- Advocacy 101 Agenda (Click here) <ul style="list-style-type: none">- Scheduling or technical support? (Phone number listed here soon)	

- The **Status** of each meeting is in the upper right hand corner (color coded)
- Most meeting times will be offset by 5 minutes (ex: 10:55pm). This is **intentional and is the start time for the meeting.** **Listed time is EASTERN TIME**

Schedule and Logistics Overview

		● Confirmed
Time	10:55 AM	
Office Of	Senator David Perdue	
Meeting With	Legislative Correspondent: Kevin Gannon	
Location	Dial-in: 1-253-215-8782; Access Code: 938-568-0666#	
Party	R	
State	Georgia	
District		
Team Lead	Meryl Uganda	
Special Notes		
Talking Points	<ul style="list-style-type: none">- REMINDER: All meeting times listed are Eastern Time- REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through- REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation <ul style="list-style-type: none">- Talking Points and Leave Behind Material (Click here)- Advocacy Telephone Script (Click here)- Advocacy 101 Agenda (Click here) <ul style="list-style-type: none">- Scheduling or technical support? (Phone number listed here soon)	

- The **Status** of each meeting is in the upper right hand corner (color coded)
- Most meeting times will be offset by 5 minutes (ex: 10:55pm). This is **intentional and is the start time for the meeting.** **Listed time is EASTERN TIME**
- Conference call lines and access codes will be displayed in the **Location** field

Schedule and Logistics Overview

		● Confirmed
Time	10:55 AM	
Office Of	Senator David Perdue	
Meeting With	Legislative Correspondent: Kevin Gannon	
Location	Dial-in: 1-253-215-8782; Access Code: 938-568-0666#	
Party	R	
State	Georgia	
District		
Team Lead	Meryl Uganda	
Special Notes		
Talking Points	<ul style="list-style-type: none">- REMINDER: All meeting times listed are Eastern Time- REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through- REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation- Talking Points and Leave Behind Material (Click here)- Advocacy Telephone Script (Click here)- Advocacy 101 Agenda (Click here)- Scheduling or technical support? (Phone number listed here soon)	

- The **Status** of each meeting is in the upper right hand corner (color coded)
- Most meeting times will be offset by 5 minutes (ex: 10:55pm). This is **intentional and is the start time for the meeting.** **Listed time is EASTERN TIME**
- Conference call lines and access codes will be displayed in the **Location** field
- **Team Lead** indicates who will open up the conversation

Schedule and Logistics Overview

Party	D
State	Pennsylvania
District	4
Team Lead	
Special Notes	
Talking Points	<ul style="list-style-type: none">- REMINDER: All meeting times listed are Eastern Time- REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through- REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation - Talking Points and Leave Behind Material (Click here)- Advocacy Telephone Script (Click here)- Advocacy 101 Agenda (Click here) - Scheduling or technical support? (Phone number listed here soon)
Additional Attendees	Debbi Harris, Stephen Harris
Meeting Notes	<div></div> <div>Save notes</div>

- Talking points, attachments, and help number

Schedule and Logistics Overview

Party	D
State	Pennsylvania
District	4
Team Lead	
Special Notes	
Talking Points	<ul style="list-style-type: none">- REMINDER: All meeting times listed are Eastern Time- REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through- REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation- Talking Points and Leave Behind Material (Click here)- Advocacy Telephone Script (Click here)- Advocacy 101 Agenda (Click here)- Scheduling or technical support? (Phone number listed here soon)
Additional Attendees	Debbi Harris, Stephen Harris
Meeting Notes	<div></div> <div>Save notes</div>

- Talking points, attachments, and help number
- Additional attendees on the call

Schedule and Logistics Overview

Party	D
State	Pennsylvania
District	4
Team Lead	
Special Notes	
Talking Points	<ul style="list-style-type: none">- REMINDER: All meeting times listed are Eastern Time- REMINDER: Meeting time listed is the START time, call into the meeting 5 min PRIOR to the start time. If you experience a busy tone, please keep redialing you will eventually be put through- REMINDER: If a name is listed in the Team Lead field, that person will initiate and conduct the conversation- Talking Points and Leave Behind Material (Click here)- Advocacy Telephone Script (Click here)- Advocacy 101 Agenda (Click here)- Scheduling or technical support? (Phone number listed here soon)
Additional Attendees	Debbi Harris, Stephen Harris

Meeting Notes	<div></div> <div>Save notes</div>
---------------	-----------------------------------

- Talking points, attachments, and help number
- Additional attendees on the call
- Meeting Notes: please record feedback on how the meeting went. Click on the blue “Save Notes” button when complete

Schedule and Logistics Overview

- Please call into the meeting **5 minutes prior to the start time**, in order to discuss with your group on who will open up the conversation and who will be speaking.
- All times will be **Eastern Time**
- Keep redialing if a busy tone occurs, you will eventually get through
- If the Office does not join the call **within 10 minutes** of the start time, please call Prime Advocacy
- There will be a **help number** listed in the **Talking Points** section to call if you need to get ahold of Prime Advocacy
- Calls are scheduled for **15 minutes blocks**. They may end early or go longer, but the time frame remains the same as an in person meeting
- Please provide feedback on how the meeting went in the **Meeting Notes** section of each meeting

"Meeting" with Legislators

- **Prior to the scheduled call time**

- Review Materials
- Call in 5-10 minutes early
- Designate a call "leader" and choose which participant will present which issues:
 - Note who is an actual constituent
 - Consider everyone's personal experience related to the policy issues
- Identify name of the staff or elected representative you will meet with

- **Meeting**

- Clearly introduce participants and explain the mission of IDF
- Have the individual(s) you're meeting with introduce themselves
- Allow designated leader to guide the call, introducing participants when it is their turn to present an issue or tell their story

Ways You Can Get Involved



- Annual **IDF Advocacy Day** in which volunteers advocate to Congress for **federal issues** impacting the PI community
- **Health Access Advocates**, who advocate for the PI community in their home **state**
- **State Advocacy Workshops** to teach PI community members in individual states how to be effective advocates in their state legislatures
- **IDF Action Alerts** to mobilize community members to reach out to policy makers at the federal and state level
- The **Advocacy Playlist** to educate the PI community and the broader public with health policy related videos

Sign Up for IDF Action Alerts

Sign Up for
IDF
Action Alerts

5 STEPS

1. Go to **www.primaryimmune.org/action-alerts**
2. Click "**Sign Up for Action Alerts**"
3. Under "**Quick Sign Up**," enter your e-mail address and zip code.
4. On the next page, enter your information and press "**Save**"
5. Now you are ready to receive alerts and...

Make Your Voice Heard!

Questions?



Thank you!

Lynn H. Albizo

Associate V.P. of Public Policy

lalbizo@primaryimmune.org

Jamie N. Sexton

Government Relations Manager

jsexton@primaryimmune.org

Becca Russ

Grassroots Advocacy Specialist

rruss@primaryimmune.org

