IDF Virtual State Advocacy Workshop

New York
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.
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
New York State Legislature

- Bicameral body consisting of two houses: Senate and Assembly
  - 150 members of the New York State Assembly
  - 63 members of the New York Senate (number of members is flexible)
- Full-time legislature
- The Legislature convenes in the first or second week of January each year and the regular session usually takes place until late December or early January of the following year.
The Legislative Process in New York

Bill Introduced

Public Committee Hearing
*Opportunity to Testify

Final Version of Bill Must "Age" for Three Days

Vote in House of Origin

Bill Goes to Governor

Resolution of Differences

Process is Repeated in Other House

Bill Referred to Other House

Bill Becomes a Law

Bill Becomes a Law
Governor
Andrew Cuomo (D)

The governor is the head of the executive branch in New York. All bills passed by the New York 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 Assembly
Carl Heastie (D)

The Speaker is the highest ranking officer of the Assembly, and is elected by the Assembly Members usually at the beginning of each two-year legislative session. The Speaker is charged with the overall management and supervision of the Assembly. She or he appoints members to all committees and subcommittees of the Assembly, allocates funds, staffing, and other resources for the effective operation of the House, and establishes committee schedules.
The President pro Tempore is the leader of the Senate. He or she is elected by the Members at the beginning of each Session. The "Pro Tem" is the presiding officer on the Floor, overseeing the appointment of committee members, assignment of bills, progress of legislation through the Senate, confirmation of gubernatorial appointees, and overall direction of policy. He or she is also the political leader of the majority party.
Advocacy Issue in New York
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.

Despite New York’s large population, it only has a handful of plasma donation centers, largely due to unnecessary and burdensome regulations.

These burdensome regulations and resulting minimal presence of plasma donation centers in New York creates a reliance on plasma collection elsewhere and contributes to the strain on the global plasma supply.
Legislative Asks to Address this Barrier

Address Burdensome Plasma Center Regulations in New York

Support Assembly Bill 9915/Senate Bill 7811
Addressing Burdensome Plasma Center Regulations in New York

- Presently, New York’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 New York Public Health Law regulates plasma donation centers as blood collection or donation centers. This lack of distinction places burdensome and excessive regulations on the plasma donation centers in New York State, thereby limiting their efficiency and existence.

- Synchronizing New York’s laws with those in much of the rest of the country will help facilitate the establishment of an adequate number of plasma donor centers in the state.
Assembly Bill 9915 (AB9915) / Senate Bill 7811 (SB7811)

- AB9915 and SB7811 will amend the New York Public Health Law to include separate and accurate definitions of "source plasma donation center," "source plasma," and "plasmapheresis."
- Additionally, these bills will permit the collection of source plasma, including employing individuals to perform total protein tests, if the center and the individual comply with federal law and regulations.
- This legislation will synchronize New York's laws with those in much of the rest of the country.
Supporting AB9915 and SB7811

- Sponsored by Assembly Member Gottfried and Senator Rivera
- Creates a necessary distinction between plasma donation centers and blood collection or donation centers.
- Authorizes collection of source plasma at plasma donation centers that comply with federal law.
- Addresses limited plasma supply in New York by removing regulatory burdens.
- Eliminates burdensome requirements without sacrificing quality of care.
Supporting AB9915 and SB7811: Talking Points

- This bill will improve plasma donation in New York.
- Plasma donation is important to the PI community because our treatment, immunoglobulin, is made with the donated plasma.
- Therefore, the PI community relies on an adequate number of plasma donor centers in the state, which New York does not currently have.
- AB9915 and SB7811 are steps toward synchronizing New York’s laws with those in much of the rest of the country which will help facilitate the establishment of an adequate number of plasma donor centers in the state.
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!
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

- 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
<table>
<thead>
<tr>
<th>Time</th>
<th>10:55 AM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Of</td>
<td>Senator David Perdue</td>
</tr>
<tr>
<td>Meeting With</td>
<td>Legislative Correspondent: Kevin Gannon</td>
</tr>
<tr>
<td>Party</td>
<td>R</td>
</tr>
<tr>
<td>State</td>
<td>Georgia</td>
</tr>
<tr>
<td>District</td>
<td></td>
</tr>
<tr>
<td>Team Lead</td>
<td>Meryl Uganda</td>
</tr>
</tbody>
</table>

**Talking Points**
- 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)*
Schedule and Logistics Overview

- **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

<table>
<thead>
<tr>
<th>Time</th>
<th>10:55 AM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Of</td>
<td>Senator David Perdue</td>
</tr>
<tr>
<td>Meeting With</td>
<td>Legislative Correspondent: Kevin Gannon</td>
</tr>
<tr>
<td>Party</td>
<td>R</td>
</tr>
<tr>
<td>State</td>
<td>Georgia</td>
</tr>
<tr>
<td>District</td>
<td></td>
</tr>
<tr>
<td>Team Lead</td>
<td>Meryl Uganda</td>
</tr>
</tbody>
</table>

**Special Notes**

- **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

- 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

- 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.

<table>
<thead>
<tr>
<th>Time</th>
<th>10:55 AM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Office Of</td>
<td>Senator David Perdue</td>
</tr>
<tr>
<td>Meeting With</td>
<td>Legislative Correspondent: Kevin Gannon</td>
</tr>
<tr>
<td>Party</td>
<td>R</td>
</tr>
<tr>
<td>State</td>
<td>Georgia</td>
</tr>
<tr>
<td>District</td>
<td></td>
</tr>
<tr>
<td>Team Lead</td>
<td>Meryl Uganda</td>
</tr>
</tbody>
</table>

**Special Notes**
- **REMEMBER**: All meeting times listed are **Eastern Time**.
- **REMEMBER**: 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.
- **REMEMBER**: 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

- **Talking points, attachments, and help number**

<table>
<thead>
<tr>
<th>Party</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
<td>Pennsylvania</td>
</tr>
<tr>
<td>District</td>
<td>4</td>
</tr>
</tbody>
</table>

**Team Lead**

**Special Notes**

- **Talking Points**
  - 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**

[Save notes]
Schedule and Logistics Overview

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

<table>
<thead>
<tr>
<th>Party</th>
<th>0</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
<td>Pennsylvania</td>
</tr>
<tr>
<td>District</td>
<td>4</td>
</tr>
</tbody>
</table>

**Team Lead**

**Special Notes**

- 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
## Schedule and Logistics Overview

<table>
<thead>
<tr>
<th>Party</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>State</td>
<td>Pennsylvania</td>
</tr>
<tr>
<td>District</td>
<td>4</td>
</tr>
</tbody>
</table>

### Team Lead

### Special Notes
- 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 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)

### Additional Attendees
Debbi Harris, Stephen Harris

- 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

### Additional Attendees
Debbi Harris, Stephen Harris

[Meeting Notes]

![Save notes button]
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

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