Jamie N. Sexton  
*Director of State Policy*

jsexton@primaryimmune.org

Lynn H. Albizo  
*Vice President of Public Policy*

lalbizo@primaryimmune.org

Becca Russ  
*Grassroots Advocacy Specialist*

rruss@primaryimmune.org

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**Agenda**

- About IDF & PI
- Advocacy Day Priorities
- Effective Advocacy
- Legislative Meeting Logistics
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)

There are more than 400 of these rare, chronic disorders in which part of the body's immune system is missing or functions improperly. These diseases are caused by hereditary or genetic defects and are not contagious. Some disorders present at birth or in early childhood, but anyone can be affected, regardless of age or gender.
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.
Legislative Priorities

Protections for the Immunocompromised
Awareness of Plasma Donation
Access to Healthcare in the Home
The pandemic highlights the need for governments to ensure protections for the immunocompromised and to learn from their experiences when developing broad policies.

Representing those with primary and secondary immunodeficiencies, including individuals with PI, HIV/AIDS, autoimmune diseases, cancers and organ and bone marrow transplants.

IDF formed the **Protecting the Immunocompromised Collaborative**

- Engaging in advocacy to protect individuals during the COVID-19 pandemic, including vaccine access, flexible policies related to accessing services in the home and addressing caregiver burdens
- Initiated in response to the COVID-19 pandemic but will continue as an ongoing effort beyond the public health emergency
- Information and recording of Congressional Briefing held on March 17 available at [primaryimmune.org/takingaction](http://primaryimmune.org/takingaction)
Supporting Education on Plasma Donation

- Many with PI receive immunoglobulin (Ig) replacement therapy, derived from source plasma, to replace the antibodies they cannot sufficiently produce
- Source plasma is used to develop a number of therapies, and convalescent plasma with COVID-19 antibodies is used to treat some with COVID-19
- Source plasma supply is limited and donations are down due to the pandemic
- The Department of Health and Human Services (HHS) must include source plasma donation awareness as part of their blood donation campaign efforts
Ensuring Permanent Access to Home Healthcare

Because individuals with PI are so susceptible to infections, it is essential for them to have continued access to and coverage of:

- Infusions provided in the home, including Ig replacement therapy
- Telehealth services as an option for some medical care
Medicare IVIG Demonstration

- In December 2020, the Medicare IVIG Demonstration passed Congress, ensuring enrolled beneficiaries with PI continued coverage for in-home infusions through 2023 and raising the cap on enrollment from 4000 to 6500.
- The PI community is thankful to Congress for extending the Demo.
- IDF has urged the Centers for Medicare and Medicaid Services (CMS) to provide a permanent benefit for IVIG provided at home before the demonstration expires and may reach out to Congress for support if needed.
Extend Telehealth Access

- Because of the policy changes implemented during the public health emergency, people with PI have had access to telehealth services.
- While private insurers have varying policies surrounding telehealth coverage, Medicare coverage policies strongly influence private insurance coverage policies and practices. Legislation to remove barriers to telehealth services and to make permanent temporary flexibilities within Medicare will help expand telehealth access generally.
S 368/HR 1332: Telehealth Modernization Act

- Removes the restrictions on the location of the patient, allowing patients to receive telehealth wherever they are, including in the home
- Allow HHS to expand the types of practitioners eligible to practice telehealth
- Makes it easier for HHS to add new services eligible to be done via telehealth
- Allows Federally Qualified Health Centers (FQHCs) and Rural Health Clinics (RHCs) to provide telehealth services
- Allows telehealth use for required “face-to-face” visits for hospice care
# Sponsors for S 368/HR 1332: Telehealth Modernization Act

## Senate

<table>
<thead>
<tr>
<th>Senator</th>
<th>First Name</th>
<th>Party</th>
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<tr>
<td>Schatz</td>
<td>Brian</td>
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<td>Wicker</td>
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<td>Blackburn</td>
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<td>Marshall</td>
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## House

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<td>Griffith</td>
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<td>Baird</td>
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HR 366: Protecting Access to Post-COVID-19 Telehealth Act

- The Secretary of Health and Human Services (HHS) may temporarily waive any telehealth restrictions during future public health emergencies with additional permission from Congress.
- Requires a report on telehealth utilization and access during the pandemic.
- Allows FQHCs and RHCs to provide telehealth services.
- Removes restrictions on the patient's location, allowing patients to receive telehealth wherever they are, including at home and sites designated by HHS.
Sponsors for HR 366: Protecting Access to Post-COVID-19 Telehealth Act

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CONNECT for Health Act
(To Be Reintroduced)

Provisions covered in HR 366 and S 368/HR 1332 as well as:

- Allowed HHS to waive restrictions on providers, modalities, and services
- Expanded access to telebehavioral health services, including in the home
- Expanded access to tele-emergency services
- Made it easier for HHS to add new services eligible to be done via telehealth
- Expanded access to telehealth in Native American health facilities
- More provisions that would remove telehealth barriers
Legislative Ask

Support the Telehealth Modernization Act & Protecting Access to Post-COVID-19 Telehealth Act

- These are bipartisan pieces of legislation
- Ask House Representatives to co-sponsor HR 1332 & HR 366
- Ask Senators to co-sponsor S 368
- Share fact sheets with everything legislators need
- If you have any questions or need follow up information, please contact IDF for more details.
Points to Include

- **Thank legislators** from previous Congress for passing legislation that extended the *Medicare IVIG Demonstration* and share that our ultimate goal is to make this benefit permanent. IDF may call on you to help with CMS advocacy if needed.

- **Share information** about the *Protecting the Immunocompromised Collaborative* and *Plasma Donation Awareness*

- **Advocacy Ask**: Please cosponsor legislation to expand telehealth access
  - For Representatives, please support HR 1332 & HR 366
  - For Senators, please support S 368
  - Also please support the Connect Act when it is reintroduced

- **Please contact IDF** with any questions or follow up
Effective Advocacy
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
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
Congressional Meeting Logistics

- Groups will include attendees from the same state
- Groups will **not** include an IDF staff person
- Congressional meetings will occur via Zoom, although some offices may choose not to utilize the video feature
- All meetings are scheduled in Eastern Standard Time
- Meetings are scheduled for 15 minutes. They may end early or go longer, but they are scheduled the same as an in-person meeting.
Meeting with Legislators: Prior to the Call

- Review Materials
- Chat with your fellow meeting participants
- 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 member of congress you will meet with
Meeting with Legislators: During the Call

- Clearly introduce participants and explain the mission of IDF
- Have the individual(s) you’re meeting with introduce themselves
- Succinctly describe the issues
- Share a concise, poignant personal story linked to the issue
- Ask clearly what you want the legislator to do
- Offer IDF as a resource
- Say THANK YOU!
Meeting Pointers

- Allow designated leader to guide the call, introducing participants when it is their turn to present an issue or tell their story
- Be polite even if you don’t agree with them
- If asked questions, answer them honestly. If you don’t know an answer, tell them IDF will get back to them and make note of that on the online portal in your meeting notes.
- Don’t expect member/staff to commit on the spot, provide IDF contact information for follow up
- Show appreciation for their attention and time
Making Your Pitch

- 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 the listener
Follow Up - Thank You

- You will continue to have access to the contact information of the staff and members that you meet with in the online portal after Virtual Advocacy Day.
- Provide thorough notes about your meetings in the portal.
- If you promised to provide answers or research, make sure to share that with IDF in the portal so we can help provide the information requested.
- You will be provided with a sample note for you to modify and send to your legislator(s).
- Thank you notes are not only polite, they allow you to present your **ASK** again and keeps IDF and our issues on their minds.
Grassroots Advocacy

- **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**

- **2021 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
If You Have Downtime...

- Try Out the IDF Advocacy Day 2021 Social Media Toolkit
  - Post about Advocacy Day setup and tag your elected representatives!

- Explore the IDF Patient Advocacy Engagement Toolkit
  - Primaryimmune.org/advocacytoolkit

- Learn About IDF Public Policy Priorities
  - Primaryimmune.org/advocacyplaylist
IDF Social Media

Share your experience on:

- **Facebook**
  @immunedeficiencyfoundation
- **Twitter**
  @IDFCommunity
- **Instagram**
  @IDFCommunity
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!
2021 Advocacy Day

Nick Manetto, Megan Herber, Nisha Quasba
Faegre Drinker Consulting

April 28, 2021
117th Congressional Updates
Divided Government

**Presidency:** Biden (Democratic) Administration

**Senate:** 50/50 split with Vice President Harris breaking ties
- 60 vote threshold still stands, for now, to bring most legislation to the floor
- Democratic leadership increasingly motivated to use a tool, known as reconciliation, that can pass bill with straight majority votes.
- Ongoing debate about the filibuster and pressure on Democrats from the political left to limit its use.

**House:** Remains controlled by Democrats but more narrowly than previous Congress.

**Committee Shake-Up:** Relevant health-related committees:
- Senate: HELP, Finance, Appropriations
From the President’s Desk: The American Jobs Plan

• The package totals $2.25 trillion in federal spending over eight years focusing on transportation, caregiving, manufacturing, healthcare, housing, schools, water, broadband, and the power grid.

• From a healthcare perspective, the plan would allocate $400 billion toward home-based services and caregiving by expanding home and community-based services under Medicaid as a mandatory benefit.

• President Biden is anticipated to release a subsequent package focused on additional healthcare issues, such as addressing the costs of prescription drugs and making permanent enhancements to the ACA.

• As noted previously, President and Democratic leaders in Congress appear increasingly interested in advancing legislation via “reconciliation” to overcome Republican opposition rather than seek a political compromise.
What Does this Mean for Us?

• Overall, the Administration and Congress are focusing on big-ticket items and ways to advance the policies through a closely divided Congress.

• As with the recently passed American Rescue Plan, these efforts will take up much of the oxygen in Congress from both members and staff.

• Landscape remains very fluid and will continue to be so.

• IDF will continue exploring ways to advance our community’s priorities including potentially through these measures if opportunities arise and otherwise.
How to be the Best Advocate?
Advocating Virtually During a Pandemic

• Engaging on topics outside of the coronavirus response
  • Threading the needle between focusing on our important priorities while being mindful of the bigger picture.
  • Making appropriate connections between PI and COVID-19 concerns.
  • Recognizing challenges members and staff are facing.
  • While still a major concern, the pandemic is not as all-consuming as it was during advocacy day 2020.

• “Zoom fatigue”: Nice to offer a videoconference option but don’t be upset if offices don’t accept or if response varies. Just like you, staff can and do have “Zoom” fatigue.
Basic Framework for Meetings

• With a group of advocates, ensure you assign roles and have a basic plan for who will say what ahead of time.
• Who you are and why you care about PI. Make it personal!
• Where you are from (geographic location and IDF)
• What you want them to know about PI and what actions you want them to take.
• Why should the office care about issues of importance to our community (history, leadership on the issue, committee, etc.)
• What questions do they (staffer/member) have for you?
• When and how can you follow up? Can you obtain their email address?
• How else can you be helpful?
General Advice

✓ Always thank the Member/staffer for their time and add extra thanks if they are a champion of your issue.

✓ Be concise. Explain background, but assume you have 10 minutes or less to get all your points across.
  ○ While trying to get points across quickly, try to slow your speech down to make it digestible and conversational.

✓ Be friendly and allow for personal conversation and connections as appropriate – hope you had a nice holiday, I’m sure you’re very busy this week, etc. Some conversations may turn into 20 minutes about a sports team or politics, and that’s great to make that connection with staff, but be sure to squeeze in your points/ask quickly as well.

✓ Be positive. Even if the meeting becomes contentious on an issue, be sure to end the meeting on a positive and gracious note.

✓ Be prompt with follow-up. If you promised to get back to the office on three points, get back to them within the day or two. If one data point is not easily attainable, acknowledge that you are missing one follow-up item and let them know you are working on it and will follow up as soon as possible. Even if you don’t have any follow-up responses, thank the staff with whom you met within 3 days of your meeting. Use this contact info wisely including to follow-up and deepen the connection during the course of the year. The best advocates engage year-round!

✓ Do not be political. On advocacy day, your priority is the PI community; not personal politics.
2021 Advocacy Day Priorities

- Protections for the Immunocompromised
- Awareness of Plasma Donation
- Access to Healthcare in the Home
Protecting the Immunocompromised Collaborative

• Policy Letters and Submissions on COVID-19 Issues

• March 17, 2021: Hosted a Congressional Briefing highlighting COVID-19 Challenges for the Immunocompromised:
  • Accessing Care: Technology can reduce delays and interruption but not a full substitute
  • Caregivers: The frequently forgotten who need attention
  • COVID-19 Treatments & Vaccines: Not a one-size-fits-all approach
Extension of the Medicare IVIG Demonstration Project

• Rep Matsui (CA-6) & Rep Brady (TX-8) bill passed end of 2020
  • Extended the demonstration for three years (2023)
  • Expanded the cap on enrollment from 4000 to 6500 individuals.

• Thank Members

• Continued advocacy for permanent benefit
Plasma protein therapies are unique and non-interchangeable treatments for individuals afflicted with a variety of rare chronic and life-threatening conditions.

The availability of plasma protein therapies is highly dependent on the collection of donated plasma which, through a complex and time-consuming process, is developed into plasma protein therapies.
The Committee recognizes that plasma protein therapies are unique and non-interchangeable treatments for individuals afflicted with a variety of rare chronic and life-threatening conditions. The availability of plasma protein therapies is highly dependent on the collection of donated plasma which, through a complex and time-consuming process, is developed into plasma protein therapies. The Committee is concerned about growing demand for such therapies concurrent with disruptions in collection, distribution and manufacturing of plasma protein products due to the COVID-19 pandemic. To foster confidence in donating plasma to ensure adequate supply, the Committee directs the Department to conduct an education and awareness campaign on the importance of source plasma donation and the safety of the process as part of the larger campaign around the safety of blood donation broadly.
### Bipartisan Telehealth Bills

<table>
<thead>
<tr>
<th>S 368/HR 1332: Telehealth Modernization Act</th>
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<tr>
<td>✓ Remove the geographic and originating site restrictions on the location of the patient, allowing patients to receive telehealth wherever they are, including in the home;</td>
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Thank You!
If you have any questions, please contact Becca Russ at rruss@primaryimmune.org
A Special Thank You to...

CLS Behring Grifols Takeda

Whose Generous Support Made This Program Possible
Online Schedules and Logistics Overview
Receiving Your Schedule

- You will receive an automated email from Advocacy Associates on a **to-be-determined date** by your organization.

- Click on the URL to access your schedule. You will be automatically logged in when clicking on the URL.

- Check your SPAM/JUNK folder if you think you did not receive the email.
  - Verify with your organization on the date schedules were/will be sent.

- Follow your email platform’s instructions for unmarking future correspondence as spam, if needed.
Not Able to Login?

- If you are not able to login or become logged out at any point, you will land at a login page.
Not Able to Login?

- If you are not able to login or become logged out at any point, you will land at a login page.

- Select “Send me a sign-in link” – **do not** try to enter a username or password.
Not Able to Login?

- If you are not able to login or become logged out at any point, you will land at a login page
- Select “Send me a sign-in link” – do not try to enter a username or password
- Input the email you registered for the event with to receive a new link to your schedule
Not Able to Login?

- If you are not able to login or become logged out at any point, you will land at a login page.
- Select “Send me a sign-in link” – do not try to enter a username or password.
- Input the email you registered for the event with to receive a new link to your schedule.
- If the problem persists, click on the Support tab.
Not Able to Login?

- If you are not able to login or become logged out at any point, you will land at a login page
- Select “Send me a sign-in link” – **do not** try to enter a username or password
- Input the email you registered for the event with to receive a new link to your schedule
- If the problem persists, click on the Support tab
- Fill out the questionnaire, and Advocacy Associates will contact you shortly
Main Schedule Page
- Confirmed meetings display on the top
<table>
<thead>
<tr>
<th>Date</th>
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<td>Wednesday, January 27, 2021</td>
<td>Rep. Greg Pence (R) [IN-06]</td>
<td>09:00 AM</td>
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<td>Virtual Meeting: Click for details on how to join. You will be able to join online or by conference phone number. Hillary Lassiter, Legislative Director; Rep. Greg Pence</td>
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<td>Rep. Trey Hollingsworth (R) [IN-09]</td>
<td>10:00 AM</td>
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<td>Sen. Mike Braun (R) [IN]</td>
<td>11:00 AM</td>
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<td>Virtual Meeting: Click for details on how to join. You will be able to join online or by conference phone number. Adam Battilo, Legislative Aide; Rally Inman, Health Legislative Assistant; Sen. Mike Braun</td>
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<td>Sen. Todd Young (R) [IN]</td>
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- Confirmed meetings display on the top
- Pending meetings display on the bottom
Main Schedule Page
- Confirmed meetings display on the top
- Pending meetings display on the bottom
- All times will be displayed as EASTERN
Main Schedule Page
- Confirmed meetings display on the top
- Pending meetings display on the bottom
- All times EASTERN
- Click on each meeting to access the information

### Your Meetings - Virtual Advocacy Day 2021

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<tr>
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<td>Rep. Greg Pence (R) [IN-06]</td>
<td>Virtual Meeting: Click for details on how to join. You'll be able to join online or by conference phone number. Hillary Lassiter, Legislative Director; Rep. Greg Pence</td>
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<td>Sen. Mike Braun (R) [IN]</td>
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### TBD

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<td>Sen. Todd Young (R) [IN]</td>
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Wednesday January 27, 2021 at 09:00 AM Eastern

Rep. Greg Pence (R) [IN-06]
Meeting With: Hillary Lassiter, Legislative Director, and Rep. Greg Pence,
Meeting Lead: June Smith

Talking Points
Please consider a funding level of $2.1 billion for FY2021.
Will the Senator/Representative co-sponsor S. 123/H. 1254?

Documents
About Us
Best Practices for Virtual Meetings

Attendees
John Green, fakeemail@thisissuperfake.com, 342-555-6789
YP1 Consulting
June Smith, junesmith@gmail.com, 123-555-6789
ABC Company
Date and Time

Meeting With: Hillary Lassiter, Legislative Director; and Rep. Greg Pence.

Talking Points

- Please consider a funding level of $2.1 billion for FY2021.
- Will the Senator/Representative co-sponsor S. 123 and H. 1234?

Documents

- About Us
- Best Practices for Virtual Meetings

Attendees

- John Green, YPI Consulting: fakeemail@thisissupafake.com, 342-555-6789
- June Smith, ABC Company: junesmith@gmail.com, 123-555-6789

You Have Checked In

Send Thank You Note

Meeting Report Form

Take Notes

Member Attended

Member did not attend
- Date and Time
- Meeting With
- Meeting Lead (if applicable)
- Date and Time
- Meeting With
- Meeting Lead (if applicable)
- Click “Join Online Meeting” to open video component (not all meetings will have a video component)
- **Date and Time**
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- **Meeting Lead (if applicable)**
- **Click “Join Online Meeting” to open video component (not all meetings will have a video component)**
- **Dial-in/additional information**
- **Talking Points**

Please consider a funding level of $2.1 billion for FY2021.

Will the Senator/Representative co-sponsor S. 123/H. 1234?
- Talking Points

- Documents (click to open in separate tab)
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- Documents (click to open in separate tab)
- Attendees who are in the meeting
- Talking Points
- Documents (click to open in separate tab)
- Attendees who are in the meeting
- Peer-to-peer chat function
- Talking Points
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- Check-in to report attendance
- Talking Points
- Documents (click to download as PDF)
- Attendees who are in the meeting
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- Check in to report attendance
- Thank You email. Open the email with your native platform or copy paste into Gmail, Yahoo, AOL etc.
Meeting Report Form, scroll down to answer each question
- Take Notes option
  (blank notepad)
- Take Notes option (blank notepad)
- Member of Congress attendance, check one
- Take Notes option (blank notepad)
- Member of Congress attendance, check one
- Social Media share buttons
- Take Notes option (blank notepad)
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- Click on Meetings tab to access main page again
- Take Notes option (blank notepad)
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- Click on Meetings tab to access main page again
- Click Legislators tab to access more information
Rep. Greg Pence (R) [IN-06]

Bio:

Greg Pence represents Indiana’s 6th District, where he lives with his wife Denise in Columbus. He is a proud husband, father, grandfather. Marine officer and small businessman who will ensure Indiana’s 6th District continues its strong tradition of leadership in Congress. Joining the Marine Corps in 1979 in his hometown of Columbus, Pence considers his role in Congress as a new opportunity to serve the community, state, and country that he loves. Pence understands that the 6th District needs a leader who will prioritize constituents and ensure Hoosiers always have a seat at the table. “It is an honor and a privilege to serve the people of Indiana’s 6th District.” Pence said, “I will always put Hoosiers of the 6th District and Indiana first.” Pence serves on the House Transportation & Infrastructure Committee, and the House Foreign Relations Committee in the 116th Congress. “My priorities will always include job creation, economic growth, and the protection of our conservative values in Washington.” Pence said. “I look forward to this tremendous honor to represent the place I live and the only place I will ever call home.”

Call: 202-225-3021
Birthday: November 14, 1956
Gender: M
Religion: Catholic

Bio and social media contact information:
Bio and social media contact information

Relevant bills with voting record
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- Committee assignments
- Messages tab to access peer-to-peer messages
- Directory tab to contact any attendee in your event
- Support tab for scheduling or technical assistance

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- Click the “More” tab to access additional materials, information, and resources that your organization may have provided.
Relevant Information and Reminders

- Check your SPAM/JUNK folder to ensure you didn’t miss the email with the link to your schedule (domain is @advocacyassociates.com)

- Please call/video into the meeting 5 minutes prior to the start time, in order to discuss with your group on who will open the conversation and who will be speaking

- All times will be Eastern Time (New York Time Zone)

- You will receive a reminder email 1 hour prior to each meeting from Advocacy Associates with a link to your schedule

- If the office does not join the meeting within 10 minutes past the start time, contact Advocacy Associates

- There will be a help number listed in the Support tab to call if you need to get ahold of Advocacy Associates

- Meetings 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

- Any changes to your schedule the day of the event will be sent to you via email. Please be sure to check regularly throughout the day

- Make sure you are in an area with a good Wi-Fi connection

- Mute your microphone if you are not speaking

- Know your audience - ensure you have an appropriate background
Online Schedules and Logistics Overview