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.
IDF provides accurate and timely information, resources, and support for patients and families.
Legislative Requests
Advocating on Behalf of the PI Community for

Access to Quality Care

Screening and Diagnosis

Protections for the Immunocompromised

Research & Emerging Therapies
IDF Advocacy Day 2020 Asks

Make the Medicare IVIG Demonstration a Permanent Benefit

Support the Preserving Patient Access to Home Infusions Act
Medicare IVIG Demonstration (Demo)

Establishing a Permanent Medicare Benefit for At-Home IVIG Treatments

- Extend the current Demo to allow Medicare coverage of at-home IVIG beyond 2020
- Increase/Eliminate the cap on enrollees for the Demo
- Transform the Demo into a permanent benefit
Demo Background

- In 2012, Congress passed the Medicare IVIG Access Act, which established a Medicare demonstration that allowed enrollees with PI to receive intravenous immunoglobulin therapy (IVIG) in the home.
- In 2017, the Medicare IVIG demonstration was extended through December 31, 2020.
- The Demo, which aids thousands of individuals with PI by covering life-saving IVIG treatments in their home, will end on December 31 if no Congressional action is taken.
Impact on PI Community

- Extension of the Demo will ensure that individuals with PI will not experience a lapse in coverage for their in-home infusions under Medicare Part B
- Medicare beneficiaries with PI will continue to be reimbursed for the medication, supplies and services necessary for at-home IVIG treatments
- All Medicare beneficiaries with PI will have access to a permanent benefit that covers IVIG treatments in the safety of their own home
Medicare IVIG Demo Legislative Ask

Urge Congress to take appropriate steps to extend the Demo and to make in-home IVIG treatments a permanent benefit under Medicare.

Share your concerns about:

- The challenges of not being able to receive IVIG at home
- Possible lapses in coverage of in-home IVIG treatments
- The cost of at-home treatments if coverage is not continued
Preserving Patient Access to Home Infusions Act (S3457/HR6218)

Ensuring the Permanent Benefit for At-Home SCIG Treatments Provides Adequate Access for Beneficiaries with PI

- Clarifies the intentions of the 21st Century Cures Act
- Ensures appropriate payment for education and training on SCIG infusions in the home
- Allows benefits to cover various services and supplies needed for at-home SCIG infusions
In December 2016, Congress passed the 21\textsuperscript{st} Century Cures Act, which included a services fee to pay for items and professional services needed for in-home SCIG therapy.

At the last minute, a provision was inserted that delayed the fee for 4 years.

In January 2021, Medicare is scheduled to implement the permanent home infusion services benefit to support access to nursing, training and other services needed to deliver SCIG and drugs infused using pumps in beneficiary homes.

However, some updates are necessary to ensure that all SCIG therapies now covered will continue after January 1.
Patient Access Act Key Provisions

- Ensures that certain treatments that require patient training, education and ongoing support by a nurse are eligible for such services payments, even if they are considered “self-administered”
- Includes important pharmacy services as covered services
- Permits payment for services on any date that a beneficiary receives a drug regardless of whether a nurse or other provider is present
Impact on PI Community

- Enables the delivery of infused medications to patients’ homes
- Allows vulnerable individuals to avoid facilities with other patients to decrease risk of exposure to pathogens, including COVID-19
- Creates savings for patients by moving care into more cost-effective home settings
Sponsors of H.R. 6218

Sponsor: Rep. Elliot Engel [D-NY-16]
Cosponsors (as of 4/1/2020)

**Democrats**
- Rep. Terry Sewell [AL-7]
- Rep. Robin Kelly [IL-2]

**Republicans**
- Rep. Fred Upton [MI-6]
Sponsors of S. 3457

Sponsor: Sen. Mark Warner [D-VA]
Cosponsors (as of 4/1/2020)

Democrats

Republicans

Sen. Tim Scott [R-SC]
Legislative Ask

Support the Preserving Patient Access to Home Infusion Act

- This is a bipartisan Act
- Ask House Representatives to co-sponsor HR 6218
- Ask Senators to co-sponsor S 3457
- Share fact sheets with everything legislators need – No worries if you don’t remember all the details
Points to Include

1. **Advocacy Ask**: Please consider supporting the establishment of a permanent benefit for at-home IVIG treatment under Medicare Part B or at a minimum, extension of the Demo.

2. **Advocacy Ask**: Please consider cosponsoring the Preserving Patient Access to Home Infusion Act.
   - For Representatives, please support HR 6218.
   - For Senators, please support S 3457.

3. If you have any questions or need follow up information, please contact IDF for more details.

4. If you encounter any constituents who are affected by primary immunodeficiency, please use IDF as a resource.
Thank you!
Effective Advocacy
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**
- **2020 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
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
Talking Points

- People with PI have missing or 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 costly and inaccessible to those without adequate health coverage.
- People with PI often have comorbid conditions that may require expensive treatments.
- Full access to affordable treatments using the method of administration and site of care most appropriate for each individual is a priority for IDF.
"You can’t walk the halls, but you can make the calls”

IDF Advocacy Day 2020
Congressional Call Logistics

- Groups will include attendees from the same state
- Groups will **not** include an IDF staff person
- Identify the constituent, any special relationships, and the meeting “leader” before each call
If You Have Downtime...

Try Out the IDF Advocacy Day 2020 Social Media Toolkit

- Post and tag your elected representatives

Learn About IDF Public Policy Priorities

- Primaryimmune.org/advocacyplaylist

Read How IDF is Responding to COVID-19

- Primaryimmune.org/coronavirus
“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 member of congress 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
Conducting the “Meeting”

- Introductions are important
- 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!**
What to Know About Meetings

- All conference call meetings are scheduled in Eastern Standard Time
- Conference call 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 Pointers

- 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 Advocacy Day.
- Provide thorough meeting notes about your conference call meetings in the online portal.
- If you promised to provide answers or research, make sure to share that with IDF in the online 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 member.
- Thank you notes are not only polite, they allow you to present your ASK again and keeps IDF and our issues on their minds.
IDF Social Media

Share your experience on:

- Facebook
  www.facebook.com/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!
Thank you!

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Tips for Advocating in a Virtual World

Nick Manetto & Megan Herber
Faegre Drinker Consulting

April 23, 2020
A Congress Turned Upside Down
<table>
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<th>BC – January until early March</th>
<th>AC – Mid March Onward</th>
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<tr>
<td>2020 was seen as a time for limited legislative activity with most energy focused on the election.</td>
<td>Lawmakers consumed by COVID-19 response.</td>
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<td>Limited agenda focused on health extenders, drug pricing, surprise billing, and likely a temporary spending bill.</td>
<td>Significant legislative activity oriented toward pandemic response, particularly supporting health care providers, and economic relief/stimulus.</td>
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<td>Energies also focused on lame duck legislation session and January 2021 and the next Congress and either new Administration or 2nd Trump term.</td>
<td>Coronavirus and response dominates all things Washington and will likely have a significant impact on the election, especially given difficulties voting due to social distancing.</td>
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Two Key Challenges to Advocating This year

• 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.

• Engaging with staff via phone
  ○ Limited opportunity to make small talk and other connections.
  ○ Potential for staff distraction/multi-tasking.
  ○ Need for coordination, being concise, and clarity.
Coordination

• Have clearly defined speaking roles for each meeting participant, particularly a leader/facilitator for each meeting.

• Leader/facilitator should open the call
  ○ Thank staff/member for their time and recognize the extraordinary circumstances.
  ○ Play a moderator role by introducing themselves and others and framing the agenda.

• Make for smooth transitions to speaker and from introductions/overview to the policy ask.
  ○ Introduce/reintroduce self when speaking.
  ○ Avoid jargon.
  ○ Speaker in shorter sentences and for shorter periods of time.
Concise

• Being on the phone makes concise delivery even more important.

• Work to vary voices so no one person speaks for a lengthy period of time.

• Work to make introductory remarks and comments brief to move toward a discussion.

• Consider questions to engage the staff:
  ○ Are you familiar with Primary Immunodeficiencies?
  ○ Are you familiar with immunoglobulin therapy?
  ○ What questions can we answer for you?
Clarity

• Be very basic in describing/introducing PI for offices who are not familiar.

• Think about how you would describe PI to a person without any medical/scientific background for the very first time.

• If a staffer or member asks for more details, you can go deeper, but start at a fairly high level.

• Deliver the “ask” as you would in an in-person meeting.
I have a condition called ______ which is a primary immunodeficiency, or PI. There are hundreds of forms of PI. Every person with a PI has an immune system that does not function properly. Many people with PI, [including me], treat our disease by regular infusions of a drug called immunoglobulin.

Immunoglobulin or Ig for short is a medication derived from blood plasma contributed by thousands of donors that goes through a rigorous safety and complex development process. You can receive Ig in two ways – intravenously (IV) or subcutaneously (Sub-Q) using a special pump.
Template Call Agenda

I. **Leader** introduces self and others on the call.

II. Ask staffer/member to introduce themselves.

III. Thank staff for time and asks if they are familiar with PI.

IV. **Designated story-sharer** provides basic overview of PI and their own situation.
   - One or two other participants may share of brief stories, especially if they’re constituents.

V. **Leader** addresses policy agenda/asks; consider an initial question or questions such as:
   - Are you familiar with home infusion treatments?

VI. Articulate the ask and transition to discussion, Q&A, with staffer.
   - Only answer questions you know the answers to – feel free to say “we will get the information and get back to you” if you don’t know

VII. **Leader** closes the meeting by thanking staffer/Member for the time, repeating the ask and asking if they can follow-up over the coming weeks.
2020 Congressional Request

- Extend the Medicare in-home IVIG demonstration so beneficiaries do not lose access to in-home IVIG at the end of the year and to move toward a permanent benefit in-home IVIG benefit.

- Cosponsor the Preserving Patient Access to Home Infusions Act (S. 3457, H.R. 6218) to ensure appropriate payment for education, training and other services and supplies for beneficiaries receiving SCIG.
PI and Coronavirus

• You can note the challenges COVID-19 poses to people impacted by PI, particularly given our impaired immune systems.

• People with PI are more susceptible to any infections, even modest ones; threats as severe as COVID-19 are a matter of life-and-death. As people with immunodeficiencies rely on community vaccination, we also rely on community social distancing to keep us safe during this outbreak.

• The pandemic underscores the importance of widespread access to Ig therapies in the home setting. This is why we ultimately want to see permanent access to in-home IVIG therapy and adequate reimbursement for all home infusion care.
Questions?