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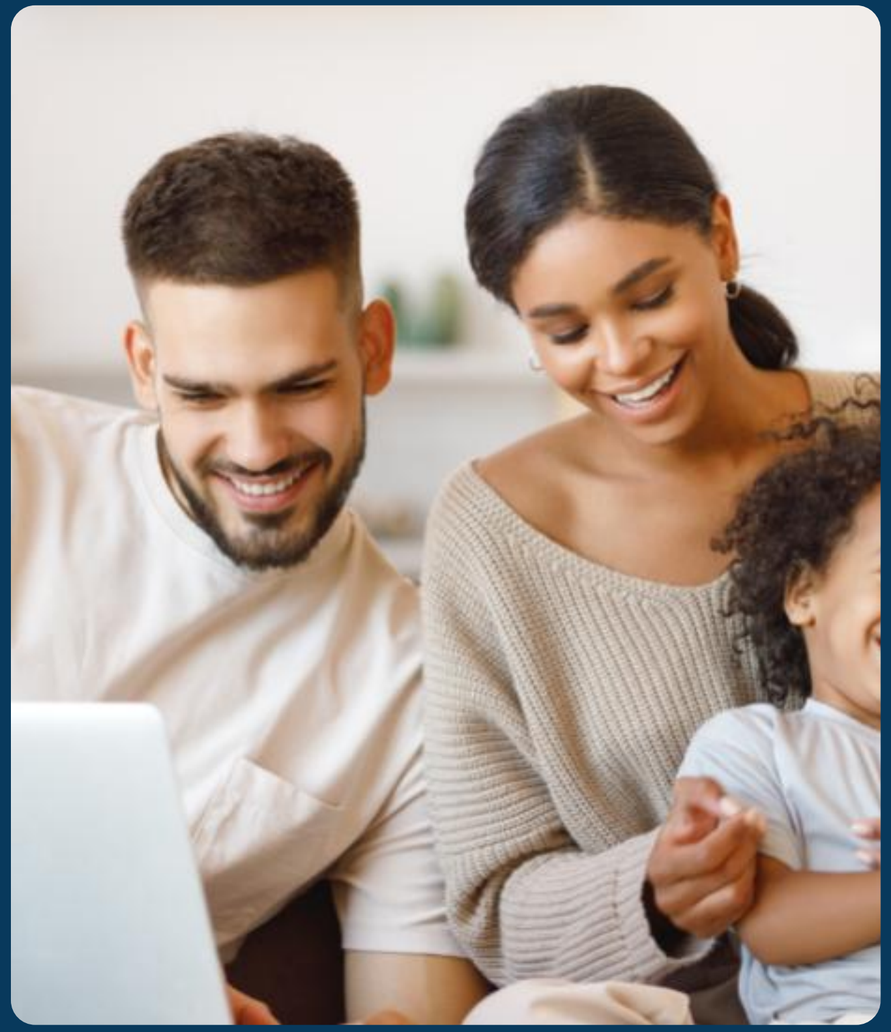
LIVING WELL WITH PI

Impact of federal policy changes on the PI community



7:00 p.m.
April 17, 2025

Mission & Vision



Mission: The Immune Deficiency Foundation improves the diagnosis, treatment, and quality of life for every person affected by primary immunodeficiency.

We foster a community that is connected, engaged, and empowered through advocacy, education, and research.

Vision: A healthier day, every day, for every person with immune deficiency.

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Disclaimers

- Immune Deficiency (IDF) education events offer a wide array of educational presentations, including presentations developed by healthcare and life management professionals invited to serve as presenters. The views and opinions expressed by guest speakers do not necessarily reflect the views and opinions of IDF.

- The information presented during this event is not medical advice, nor is it intended to be a substitute for medical advice, diagnosis or treatment. Always seek the advice of a physician or other qualified health provider with questions concerning a medical condition. Never disregard professional medical advice, or delay seeking it based on information presented during the event.



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Meet our panelists



Jorey Berry

President and CEO
Immune Deficiency Foundation



Lynn Albizo, JD

Chief Public Policy Officer
Immune Deficiency Foundation



Angie Kotarski, BCPA

Community Resource Navigator
Immune Deficiency Foundation

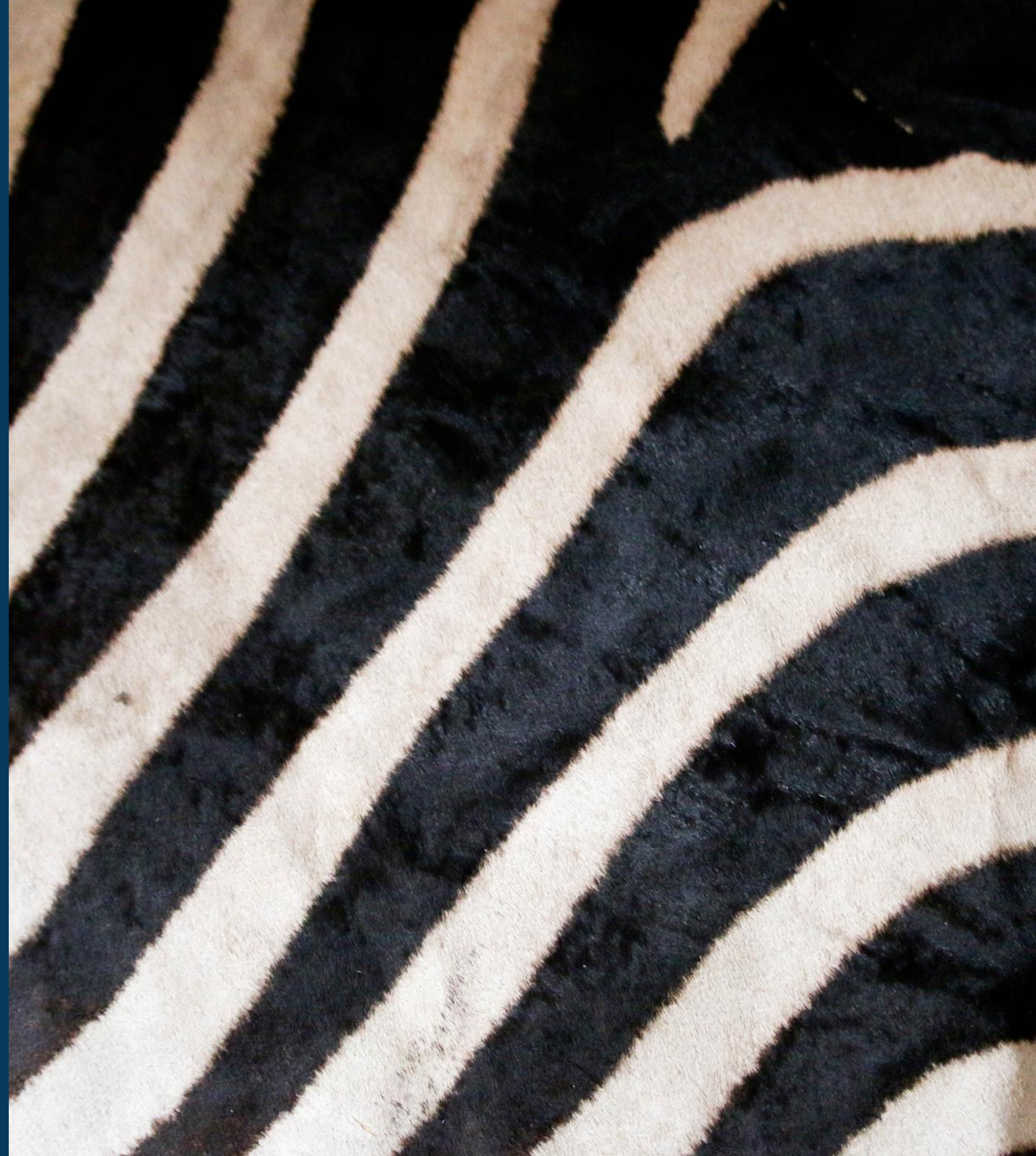


Jodi Taub, LCSW, PLLC

Psychotherapist & Owner
Jodi Taub Therapy

Our pledge to protect the PI community.

Immune Deficiency Foundation



Living well with PI: Impact of federal policy changes in 2025

Actions and priorities of the Immune Deficiency Foundation

2025: A hectic and fluid start

- New Administration (Trump 2.0)
- New 119th Congress
- Incredible amount of change and activity over short time
- Significant amounts of uncertainty

Administration dominant themes

- **Executive orders and directives**
  - Issued at a furious pace since January 20th – including MAHA Commission, withdrawal from the WHO, NIH indirect cuts.
  - Many aggressive actions (communication freeze, removal of all perceived DEI initiatives, rescission of federal funds, federal layoffs); several tied up in litigation.
- **Non-traditional agency appointees**
  - Health and Human Services (HHS) Secretary and department heads.
- **DOGE efforts to reduce size and influence of federal agencies**
  - Highly controversial effort being directed by Elon Musk.
  - Major reduction in HHS workforce.
  - Consolidation of departments.
  - Subject of intense pushback and litigation.
- **Non-heath related actions (e.g., tariffs, immigration, foreign policy)**

The 119th Congress

- **Narrow Republican majorities in the House and the Senate**
  - Opportunities to introduce ourselves to new members in both parties.
  - The administration has significant influence on Republicans.
- **Major challenges in advancing agendas**
  - Modest progress to date on major goals and objectives through the legislature.
- **Senate confirmation of cabinet and other nominees**
  - All cabinet nominees advanced.
  - Surprise withdrawal in nomination of CDC Director Dr. David Weldon; Susan Monarez, who holds a PhD microbiology and immunology is new nominee.
- **Trump legislative agenda**
  - Republicans focused on tax cuts and immigration.
  - Impact of Medicaid cuts and tariffs highlighted by democrats.

New HHS structure

- **Division Consolidation**
  - 28 HHS divisions will be consolidated to 15; and 10 regional offices will become 5
  - Administration for a Healthy America (AHA) will consolidate the OASH, HRSA, SAMHSA, ATSDR, and NIOSH
  - Divisions of AHA include Primary Care, Maternal and Child Health, Mental Health, Environmental Health, HIV/AIDS, and Workforce
  - Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) shut down.
- **Decreases in employee workforce**
  - FDA approximately 3,500. Reduction is not intended to impact drug, medical device, food reviewers, or inspectors.
  - CDC approximately 2,400. The Administration for Strategic Preparedness and Response (ASPR)—approx. 1000 individuals— will move to CDC
  - NIH approximately 1,200. Centralizing procurement, human resources, and communications across its 27 institutes and centers.
  - CMS approximately 300 employees. This is not intended to impact Medicare and Medicaid services.

Impact on IDF’s priorities

- **Decline in government support of vaccines**
  - Statement issued and joint letter submitted supporting vaccines.
  - Questions submitted at hearing.
  - Measles outbreak.
  - Weldon nomination for CDC director withdrawn.
- **Decrease NIH engagement:**
  - Planned collaboration with NIAID was halted.
  - Team uninvited to workshop initiate by congressional language we initiated.
- **Potential stall in newborn screening advancement**
  - The ACHDNC determines conditions on the Recommended Universal Newborn Screening Panel (RUSP).
  - Federal support of state NBS programs at risk of reductions.
- **Reduced access to care – targeting cuts to Medicaid**
  - House passed budget resolution cutting Medicaid.
  - Senate can reject bill and commit to protecting Medicaid.
- **Skilled nursing facility bill**
  - House champions are committed to reintroducing when more leads are secured.

What IDF is doing

- **Monitoring all government actions that could impact our community.**
- **Prioritizing advocacy issue for us to engage.**
  - **Leading and actively engaging in efforts that:**
  - Are important to and directly impact our community and mission.
  - We have the capacity, expertise and reputation to have some influence.
- **Joining coalition efforts (sign-on letters etc.) that:**
  - Impact our community directly or indirectly.
  - We don’t have the capacity or expertise to more actively engage.
- **Released a public statement, on *Federal policy changes: Pledge to protect the immunocompromised, Feb. 21, 2025.***
  - *https://primaryimmune.org/resources/news-articles/statement-federal-policy-changes-pledge-protect-immunocompromised*

Federal policy change priority statement

- **Ensuring vaccines remain accessible and supported by federal and state health agencies to protect the immunocompromised**.
  - Access to coverage.
  - Government education and support of vaccines.
- **Safeguarding public health data to monitor infectious disease and ensure experts in the field are employed and able to conduct this monitoring.**
  - Getting ahead of infection spread before another pandemic
- **Continue critical investments in research and innovation.**
  - NIH funding and support.
  - Continue funding to research institutions for research on PI and other diseases.
- **Support full access to treatment, ensuring Medicaid is fully funded.**
  - Ensure patient access to care and treatment regardless of financial situation.

Opportunities to engage

Reach out to us at idfadvocacy@primaryimmune.org for policy engagement opportunities.

- Sign up for action alerts.
  - https://primaryimmune.org/get-involved/advocate/action-alerts
- Volunteer as a health access advocate (HAA)
- Advocacy Day, May 1 (for those already registered)
- State advocacy workshops
  - June 5, Baton Rouge, LA
  - Fall, 2025 virtual workshop state and date to be determined.

Living Well With PI: Resources for staying informed

Websites and organizations to support staying up to date and locating resources.

Medicare, Medicaid, and the Affordable Care Act (ACA)

- www.medicare.gov
- www.medicaid.gov
- www.healthcare.gov





State, city, and county health departments

- www.usa.gov/state-health
- National Association of City and County Health Officials: www.naccho.org/membership/lhd-directory

Non-government health policy websites

Kaiser Family Foundation

- https://www.kff.org/

The Commonwealth Fund

- www.commonwealthfund.org/





Legal assistance

Disability insurance, benefits, access to care

- **ACCESSIA HEALTH**
  - www.accessiahealth.org
  - 888-700-7010
- **THE PATIENT ADVOCATE FOUNDATION**
  - www.patientadvocate.org
  - 800-532-5274
- **TRIAGE HEALTH**
  - www.triagehealth.org
  - 424-258-4628

Financial assistance

- Manufacturer Copay Assistance (if not on a federally funded plan)
- Non profit organizations:
  - Accessia Health Accessia Health | Health and Human
  - The Assistance Fund The Assistance Fund - TAF
  - Healthwell Foundation When health insurance is not enough - HealthWell Foundation
  - Patient Advocate Foundation Co-Pay Relief – Patient Advocate Foundation | Co-Pay Relief
  - Fund Finder Find help with FundFinder - PAN Foundation
  - Think Genetic Foundation Homepage - ThinkGenetic Foundation

GET ON THE WAITLIST!

Ask your specialty pharmacy or infusion suite for financial assistance

Get involved with IDF!

- Sign up for Action Alerts
- Become a Health Access Advocate
- Tell your story; Faces of IDF
- Attend Advocacy Day
- Volunteer as a peer support coach
- Walk for PI





Other ways to get involved

- **Rare Disease Diversity Coalition**
  - www.rarediseasediversity.org/rddc-get-involved
- **Patients Rising**
  - www.patientsrising.org/
- **National Organization for Rare Disorders**
  - www.rarediseases.org/get-involved/

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Questions?

Reach out to Ask IDF

askidf@primaryimmune.org



Emotional strategies to manage uncertainty

Jodi Taub, LCSW, PLLC
Chronic illness, rare disease, and medical trauma expert

The emotional impact of uncertainty

- Medical policy changes, disruption to research participation or funding costs can impact health care concerns.
- Uncertainty can lead to emotional dysregulation and set off a “fight or flight” response. (1)
- Health care policy changes can activate health anxiety and medical trauma responses for PI patients and caregivers.
- Online reactions from others can also trigger nervous system responses. (2)
- It’s important to stay grounded despite the uncertainty or healthcare policy, research, or funding changes.
- Uncertainty can be challenging, but effective coping strategies can help build resilience and emotional balance.
- Planning and strategy building can reduce stress responses.

Strategies for healthy social media use

- **Social media can impact mental health**: It can be helpful for connection, especially for PI related groups. (2)
- **Set boundaries:** Limit screen time and silence overstimulating content. Refrain from social media arguments.
- **Curate your feed:** Delete toxic sites and choose supportive content.
- **Take breaks:** Try “social media detox” days or limit use to specific times.
- **Engage mindfully:** Ask yourself: Is this content helping or harming me?



Actionable steps for purpose and calm

- **Check the facts:** Ask your medical team how changes could impact you directly and look to the Immune Deficiency Foundation to stay informed.
- **Maintain coping strategies:** Maintain daily routines, stay connected to friends and family members, and practice self care.
- **Seek support:** Talk to a therapist, join an IDF volunteer-led Get Connected Group or one of their therapist-led support groups. Lean on trusted friends and connect with supportive online PI groups.



CBT, ACT, and DBT coping skills strategies

- **Acknowledge & accept It** – Fighting uncertainty increases stress. Accept that some things are out of your control and focus on what you is most impactful. (3)
- **Distress tolerance:** Use self-soothing techniques like listening to music or podcast or watch a favorite TV show for purposeful distraction.
- **Pause before reacting:** Balance emotion and logic to make thoughtful decisions.
- **Reframe negative thoughts:** Challenge irrational fears and replace them with balanced perspectives.
- **Positive affirmations:** Balance anxiety and fear.
- **Behavioral activation:** Engage in meaningful activities to reduce stress and uncertainty such as exercise, getting out into nature, creative expression. (4)
- **Problem-solving:** Break problems into smaller steps and identify actionable solutions.

Grounding exercises

- **5-4-3-2-1 method:** Identify 5 things you see, 4 things you touch, 3 things you hear, 2 things you smell, and 1 thing you taste.
- **Deep breathing:** Try box breathing—inhale for 4 seconds, hold for 4 seconds, exhale for 4 seconds, and hold again.
- **Sensory anchors:** Hold an object, listen to soothing sounds, or engage in mindful movement, butterfly hug.



Healthcare communication guidelines with loved ones

- Share Your Perspective
  - Explain why a specific healthcare policy affects you personally.
  - • Highlight potential risks, access barriers, or health concerns related to the policy.
- Set Boundaries
  - Communicate when a conversation becomes too stressful.
  - Pause discussions if they trigger stress or discomfort.
- Encourage Education & Advocacy
  - Offer resources for loved ones to learn more.
  - Suggest ways they can support and advocate on your behalf.





Resources

- https://primaryimmune.org/living-primary-immunodeficiency/addressing-mental-health
- https://primaryimmune.org/living-primary-immunodeficiency/get-support/peer-support-program

References

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Thank you, panelists!

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Ask IDF



Podcasts



Publications

Learn more at primaryimmune.org

2025 Research grant applications- now open!



What: IDF's research grant applications are now open for 2025 funding.

Purpose: To support patient-centered research focused on improving the treatment, health, disease management, or diagnosis of people with PI.

How it works: Download the application and submit by June 30, 2025.

Benefits: An opportunity to have your PI research supported by the IDF.

Read more at

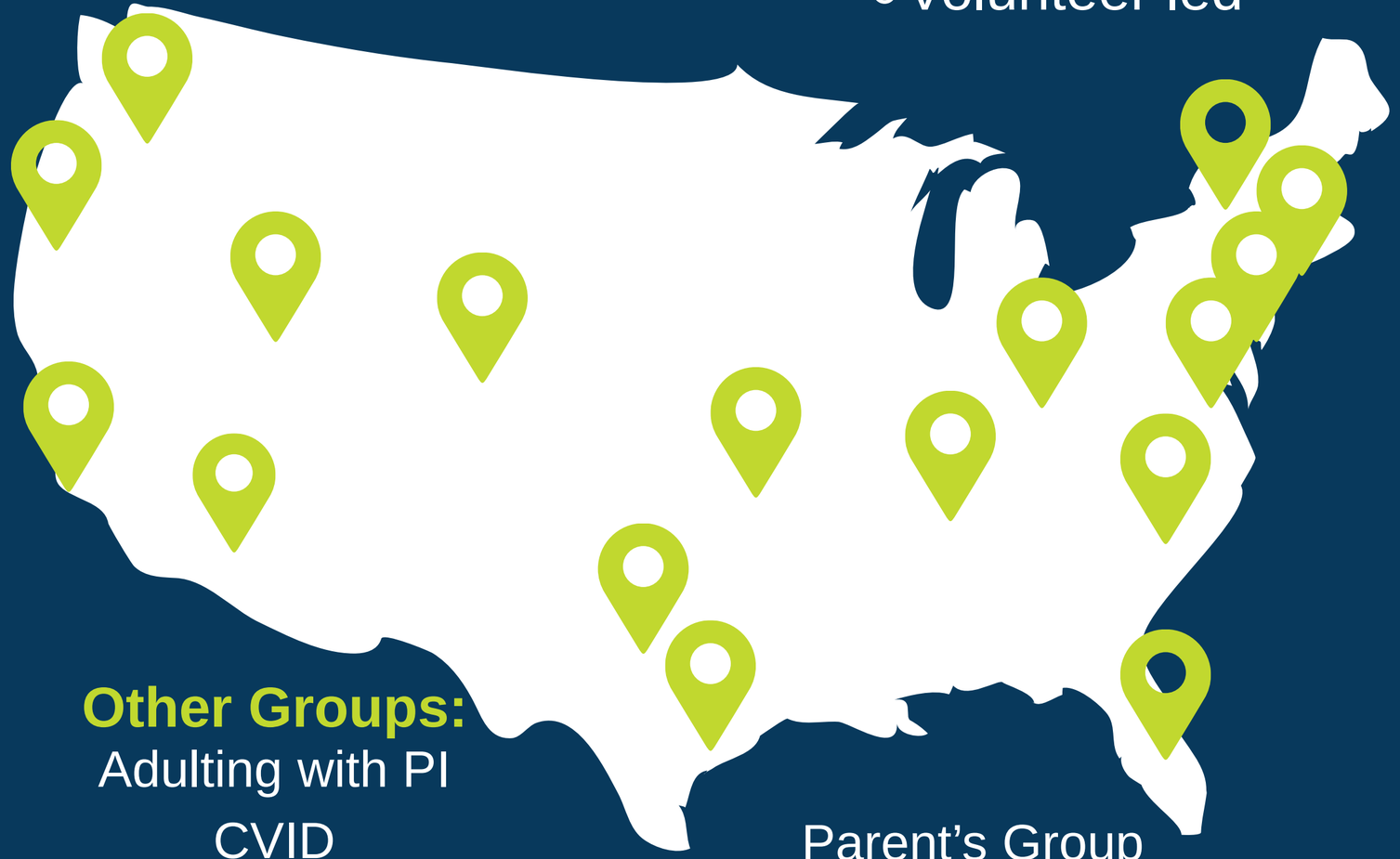
https://primaryimmune.org/resources/print-material/2025-idf-research-grant-application

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IDF Get Connected Groups

- Virtual
- Meet others with PI
- Volunteer led





Other Groups:

Adulting with PI

CVID

Healthcare Professionals

Book Club

Partners/Spouses

Parent's Group

MCAS

Golden Years, Golden Health

Early career & PI

Facilitated support groups



Young adults age 18-30



Parents & caregivers



Spouses & partners

Upcoming events this spring

Volunteer appreciation event
April 22 at 7:30 p.m ET

Compromised screening for World PI Week (via Facebook)
April 25, 2025
7:00 p.m. ET

IDF Lunch & Learn: Understanding genetic variants in APDS
May 21, 2025
12:00-1:00 p.m. ET

Thank you for joining us!

Immune Deficiency Foundation