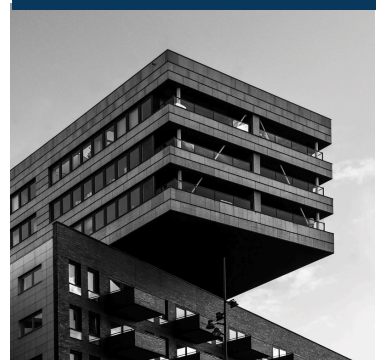




IMPACT REPORT

20
25





The architecture of care

At the Immune Deficiency Foundation, we design support with intention—building a comprehensive architecture of care that serves every individual affected by primary immunodeficiency (PI). In 2025, our strategic framework of advocacy, education, and research created a measurable impact across communities, creating a healthier day, every day, for every person with immune deficiency.

Explore our impact ▶

Awareness

Strong communities are built on shared information. In 2025, we connected with thousands through digital platforms, educational materials, and direct support, bringing critical PI resources to those who need them most.

Patients served

34,034

Our online presence

Website	Following	Views
2M website visitors 1.8M on primaryimmune.org 243k on plasmahero.org 43.4k email subscribers	 13% Facebook - 26k 18% LinkedIn - 6.7k 20% Instagram - 7.4k 146% X - 26.2k	481k views on YouTube. 2.6k Compromised screening requests.

Content impact

Publications



966 recipients of the IDF Advocate, our printed patient newsletter.



1,290 Patient and family handbooks distributed.



2,513 IDF care navigator recipients, an eNewsletter for clinician education.



3,384 publications mailed.



9,007 publication downloads.



Most downloaded

#1 Immunoglobulin product booklet, with **1,539** downloads.

Digital content created



31 new videos.

39 new podcast episodes.



16,208 podcast listens.
#1 Episode - Undiagnosed: Gaslit and gatekept

Medical outreach

Virtual medical education program

Launched an accredited continuing medical education (CME) program **equipping healthcare professionals** with the clinical education and diagnostic strategies needed to identify primary immunodeficiency (PI) in patients with recurrent infections, unexplained immune symptoms, or complex medical histories. This virtual program addresses the critical 9-15 year diagnostic delay, providing **strategies for early detection, personalized care, and overcoming access barriers**—potentially reaching hundreds of thousands of undiagnosed Americans.

FEATURING EXPERT FACULTY | JOINTLY ACCREDITED | SUPPORTED BY EDUCATIONAL GRANTS

Exhibits

Attended **14** medical exhibits interacting with approximately **2,468** clinicians—nearly 3x more than in 2024.

48 clinicians received expert consults through our **Consulting Immunologist Program**.

Educating and serving **14,134** healthcare professionals in 2025.



Engagement

Engagement is where awareness becomes action. In 2025, our community didn't just learn—they participated, connected, volunteered, and supported one another in ways that built a stronger foundation for everyone affected by PI.

Education and support



4.28 average program rating for **12** webinars with **1,436** attendees.

Our reimagined *Teen and Tween Escape* had the largest attendance ever with **152 total attendees** including **43 families** and **53 teens/tweens**.



Immune Deficiency Foundation FILMS



Worldwide reach

"Compromised: Life Without Immunity," offers an intimate look into the lives of those with primary immunodeficiency and was featured in three film festivals: the Awareness Film Festival, Social Impact Film Festival, and CINE>HEALTH Film Festival.



Community and connection



28

Get Connected
Groups across
the country



432

attended
diagnosis-specific
webinars



250

plasma
ambassadors



105

peer support
volunteers



600

active
volunteers

AskIDF



49% increase

in AskIDF submissions
related to different stages
of the PI journey with
2,226 questions answered.



Locating a PI specialist

encompassed **27%**
of the questions, making it
the #1 topic addressed by
staff.



Two days

average turnaround time in
getting our community the
answers they need.

Access

We build access at every level, from the intimacy of the exam room to the influence of legislative chambers. Throughout 2025, we connected patients with specialized clinicians and vital answers, while our advocates laid the policy foundations necessary to strengthen healthcare for the entire PI community.



Advocacy

In 2025, the Immune Deficiency Foundation led state coalition efforts that passed copay accumulator protections in Maryland, North Dakota, and Indiana. Through **three strategic advocacy workshops**, we drove victories including newborn screening legislation signed into law in Virginia and successful defense of public health protections in Louisiana. At the federal level, we opposed NIH funding cuts, advanced **vaccine access and education** through agency submissions and policy presentations, and launched **payor education initiatives** addressing insurance coverage challenges. We held a California state advocacy day on drug affordability, launched Pennsylvania digital campaigns, advocated for plasma donation access, and **supported federal copay accumulator bans** and health exchange tax credits. Through our growing **Health Access Advocate (HAA)** network, we united immunocompromised individuals across the nation to stand together and speak up for the PI community, and more.



Advocacy in action

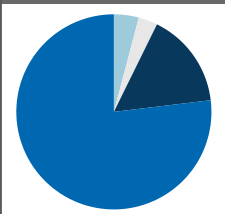
- 152** Advocacy Day participants with **32** in the **Young Advocates Academy**.
- 197** Health access advocate volunteers.
- 757** Community members who participated in email alerts.
- 3,684** Messages sent to legislators, a **36% increase** from 2024.



Health access

Our **Clinician Finder** makes it easy for patients to connect with specialists by listing provider profiles—a resource we've successfully expanded into a new state this year.

469 PI CLINICIANS | 44 STATES



Online self-assessment tool

Since the launch in 2025, more than **14,000** people have utilized the online assessment tool, with nearly half being new to our organization, to recognize possible signs of PI and create organized documentation for more productive conversations with their healthcare providers.



- 48%** scheduled healthcare appointments.
- 69%** with appointments took action within 3 months.
- 41%** used documentation with doctors.
- 48%** increased symptom awareness.
- 37%** advocated for new tests.
- 81%** rated tool highly (4-5/5).

"Thank you for validating what I experience. I used to question myself regularly."

Sustainability

Lasting impact requires strong financial infrastructure and groundbreaking research. In 2025, our community rallied to raise critical funds while our research investments advanced scientific understanding—ensuring our work endures and grows.

\$9 million in donor and sponsor support

Walk for PI	Attendees	Support
8 Locations/Cities Boston, Milwaukee, Philadelphia, San Antonio, Seattle, St. Louis, Tampa, and Virtual.	151 teams 2,252 individuals 	\$783,526 raised by the community and sponsors.

Breakthrough research

\$200,000

awarded to four researchers for advancements related to:

Michael Blaese Research Grant Award



Dr. Eric Allenspach,
assistant professor, Seattle
Children's Hospital

- Creating an affordable screening test and gene editing treatment for **IFNAR2** deficiency in underserved Arctic communities.
- Developing gene therapy for **DOCK8** deficiency that could also advance treatments for other rare diseases.
- Researching the underlying causes of allergies in **APDS** patients.
- Identifying how lysinuric protein intolerance (LPI) causes life-threatening inflammation and testing existing treatments.

Build with us



The architecture of care grows stronger with every contribution. Whether you donate, volunteer, advocate, or spread awareness, there's a place for you—a community where you belong.

Together, we're building something that lasts.



Every action builds a stronger foundation



Make a contribution

Every donation made to the Immune Deficiency Foundation helps strengthen our PI community. As a 501(c)(3) nonprofit organization, your contributions are tax deductible to the maximum extent allowed by IRS regulations.

primaryimmune.org/waystogive



Volunteer with us

Volunteers power our mission. Explore our volunteer roles: Get Connected Leaders, Plasma Ambassadors, Peer Support Coaches, Health Access Advocates, Walk Volunteers, Social Media Ambassadors, and community liaisons.

primaryimmune.org/volunteer



Ask us anything

You have questions, and we have answers. Our FREE ASKIDF service connects you with knowledgeable staff for help with IDF programs, finding physicians, treatment guidance, insurance navigation, and more. Create an account to get started.

community.primaryimmune.org/s/newask



Request educational resources

Access our library of print and downloadable materials for FREE! Available in multiple languages, our educational materials support patients, families, and healthcare professionals in every state of the PI journey.

primaryimmune.org/resources



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