



2024

ANNUAL REPORT

**Building bridges,
shaping futures.**

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Dedicated corporate sponsors and generous individual supporters fuel our mission, ensuring we can deliver vital resources and programs to our community and healthcare providers.

Our 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.



Our vision

**A healthier day, every day,
for every person with
immune deficiency.**

President's letter

As I reflect on 2024, I find myself asking a familiar question: "Do people really want to hear from me?" It's a thought that crosses my mind each time I'm asked to summarize our year, something that always feels like an impossible task. While I may hold the title of president and CEO, I'm keenly aware that I'm simply one voice within an extraordinary organization. Simply one perspective within an incredible community.

I've been in this role for three years and yet I'm still struck by the remarkable people who fuel the mission and purpose of the Immune Deficiency Foundation (IDF). Being surrounded by a community with such talent, courage, and dedication reminds me that our achievements aren't built on any single person's efforts—they're the result of collective brilliance and shared commitment.

After reflecting deeply on our accomplishments in 2024, I discovered a common theme of connection. That word, 'connection', captures the essence of who we are and how we create change. We are all more than our individual experiences. Everyone has a story and a purpose. I feel my purpose is to guide this organization to create a healthier day, every day, for every person with immune deficiency. Sometimes that responsibility feels overwhelming, but then I look around me and see all the connections and impact each one of us is making, and it drives and invigorates me to continue forward with renewed determination.

Our work isn't accomplished in isolation; it emerges from the powerful web of relationships that bind us together. I get to talk to an amazing community every day—individuals living with primary immunodeficiency (PI), their friends and family, donors, world-class medical professionals, and countless others who contribute their unique perspectives and experiences.

This year has been a testament to the power of those connections. When we developed an online self-assessment tool to help people recognize irregularities in their immune system, it wasn't just our team working in isolation. Our Medical Advisory Committee—prominent immunologists across the United States—provided the scientific foundation that made this life-changing resource possible. Now, users can discuss insights with their healthcare providers, potentially reducing diagnosis time and improving their ability to get the treatment they need.

The ripple effects continued as we expanded our healthcare network by 139%, reaching new specialists and providing them with relevant symptoms. This means more providers are equipped to recognize signs of PI, leading to faster diagnoses and better outcomes.

We also established a Community Advisory Board—stakeholders who ensure our work directly addresses the real-world needs of the PI community. This committee embodies our commitment to connection by ensuring the voices of those we serve are integrated into everything we do.

The power of in-person connection became undeniably clear when we held our first in-person conference since 2019, bringing together 997 attendees. This was the first time I had been surrounded by so many people living with PI at once, and the energy was, in a word, extraordinary. The connections made, stories shared, and support offered reminded me why our work matters so deeply. It reminded me of our purpose.

At this gathering, we debuted "Compromised: Life Without Immunity," our first feature-length documentary. The film captures the journeys of six PI community members, showing how they navigate diagnosis, treatment, and family life. Zach Moore, the director of the film and IDF's digital media manager, reflected that the documentary reveals both "the difficulty and impossibility of the decisions people affected by PI have to make" alongside "the joy they're still capable of feeling and the happiness they're still capable of finding."

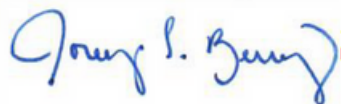
This documentary represents more than a film—it's a bridge of understanding that connects our community's experiences with the broader world. I'm so very proud of this film and so very grateful to those who entrusted us to share their personal stories.

Connection was the thread running through the entire year. Whether connecting patients with healthcare providers, medical professionals with specialized knowledge, or community members with hope, our work is fundamentally about building bridges.

The challenges facing the PI community are real and significant, but so is our collective strength. Every connection we make contributes to a future where no one faces their PI journey alone.

Thank you for being part of this connected community. Your support makes everything we do possible. Together, we are writing a story of hope, resilience, and the transformative power of human connection.

With gratitude and determination,



JOREY BERRY
President & CEO

Our leadership team

The Immune Deficiency Foundation (IDF) is driven by a visionary leadership team dedicated to creating meaningful connections that advance the lives of individuals with primary immunodeficiency (PI). This passionate group guides our strategic direction, ensuring initiatives strengthen ties between patients, families, healthcare providers, and researchers, paving the way for transformative outcomes.

Led by President and CEO Jorey Berry, our team brings together diverse expertise in patient advocacy, community development, policy reform, and organizational strategy. Each leader contributes specialized knowledge to create pathways toward improved care and promising new possibilities for the PI community.



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Chief Public Policy Officer



BRIAN LLOYD
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TAMMY C. BLACK, MPA
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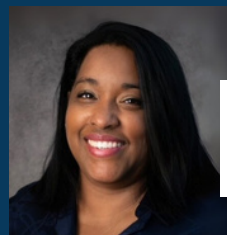
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Senior Director of Education
& Community Services



**CHRISTOPHER SCALCHUNES,
MPA**
Vice President, Research



CHRISTOPHER DUCKETT, PHR
Director of Human Resources



AIMEE YRLAS SIMPSON
Chief Development Officer

Our impact

Connecting knowledge to empowerment

Education remains a cornerstone of the Immune Deficiency Foundation's mission to support the PI community. After four years of virtual-only programming due to COVID-19, we successfully returned to an in-person format with our 2024 PI Conference, featuring **55 sessions** and nearly **1,000 attendees**.

In addition, we delivered **65 educational sessions** to over **2,400 attendees** through virtual programming and our PI Conference. These interactive sessions provided a comprehensive exploration of primary immunodeficiency, equipping attendees with the knowledge and tools to better comprehend and manage their condition.



Bridging the gap between complex medical knowledge and accessible understanding for patients, families, and healthcare providers.

112

Videos produced

298,223

Educational session views on YouTube

17,113

Publication downloads

9,000+

Individuals

1.3 million+

Website sessions connecting people with critical information, support, and resources about primary immunodeficiency.

47,042

Email subscribers

2,769

Text subscribers

Taking the first step toward diagnosis

*In September 2024, we launched an **self-assessment tool** that helps people identify potential immune deficiency symptoms. The tool provides insights that users can discuss with their healthcare provider, with the goal of reducing the time it takes to get diagnosed.*



 **558**

Patients were empowered
to take initiative in
the first 14 weeks



Ask IDF

Individuals can ask PI-related questions and get guidance to better navigate their healthcare path.



1,910+

Questions
addressed



1,496

Individuals
helped



#1

Topic: Events



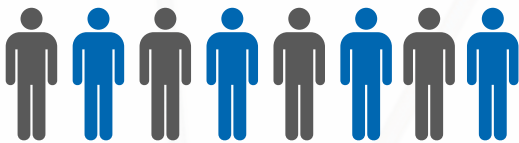
2 days

or less response
time

Empowering healthcare professionals

Healthcare providers require the same access to educational resources as patients living with PI. When we enhance awareness and knowledge among medical professionals, we enable earlier identification and faster diagnosis of PI, resulting in improved patient outcomes.

Physician consults through the Consulting Immunologist Program increased 28% compared to 2023. 



Consulted with approximately **850 medical professionals** at 10 different medical conferences.

Distributed **8** specialty-specific flyers to help healthcare professionals recognize the most relevant signs and symptoms of PI within their area of practice.



451 clinicians located in **43 different states and Puerto Rico** make up our Clinician Finder, a tool patients can use to find a medical professional near them.



We achieved remarkable growth in our healthcare professional network, expanding by nearly 139% to better serve the PI community nationwide, adding 462 new providers to our database.

Connecting communities to care

In 2024, we created meaningful opportunities for connection, both in person and online, so individuals and families living with primary immunodeficiency could find community, share experiences, and feel supported every step of the way.

Get Connected Groups

297 virtual Get Connected Group meetings were held with **1,084** participants.

Peer support

92 trained volunteers took part in our Peer Support Program, offering one-on-one guidance and encouragement to individuals navigating the challenges of primary immunodeficiency.

In 2024, we established the **Community Advisory Board (CAB)**, a vital group of stakeholders who ensure our work directly addresses the real-world needs of the PI community. This influential committee guides IDF in delivering high-quality educational and support opportunities while advising on critical clinical, advocacy, and research priorities that matter most to those living with PI.

Walk for PI

An in-person celebration of giving and growing our community!

\$751,049

Raised

2,050

Participants

176

Teams

8

cities and a virtual walk





Ben Everett, 11, shown here receiving his intravenous immunoglobulin (IVIG) replacement therapy, is one of several people with primary immunodeficiency (PI) featured in the recently released documentary, "Compromised: Life Without Immunity."

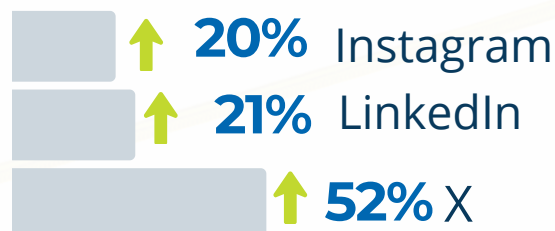


Compromised was showcased at the Entertainment 2 Affect Change's Social Impact Film Festival in New York City with an additional 490 screening requests.

Compromised: Life Without Immunity

In 2024, IDF released "Compromised: Life Without Immunity," the first feature-length film. This intimate documentary follows patients and families as they share their struggles and triumphs while medical experts offer insight into these rare diseases. The film is a heartfelt call for greater awareness, support, and understanding for the community we serve.

Strengthening connections through social media



The **IDF Podcast** continues to connect with thousands worldwide, sharing lived experiences and expert guidance throughout 2024.

92,160

Streams

10

Episodes



Connecting voices to change

Our policy work creates vital pathways between patient needs and systemic change, ensuring voices from the PI community reach decision-makers who can transform access to care, research funding, and life-sustaining therapies.

Research advocacy win:

Congressional committees directed the National Institutes of Allergy and Infectious Disease (NIAID) and the National Institutes of Health (NIH) to prioritize PI diagnostic research, leading to a February 2025 NIAID workshop featuring IDF-affiliated immunologists.

IDF continues advocating for sustained PI research funding amid federal budget constraints and agency downsizing.

Insurance reform win:

Vermont and Oregon banned copay accumulator practices that prevent patients from accessing assistance for lifesaving therapies like immunoglobulin (Ig) treatment.

IDF continues leading coalition efforts through the All Copays Count committee to eliminate these barriers nationwide and in federal plans.

Treatment access win:

Successfully reversed a major health insurer's restrictive policy on a commonly used Ig product, restoring access for numerous PI patients.

IDF continues to champion comprehensive Ig therapy access and adequate plasma donation policies to ensure sufficient supply.



38

Letters signed & sent to legislators



149

Legislative meetings



765

Individuals participated in email alerts

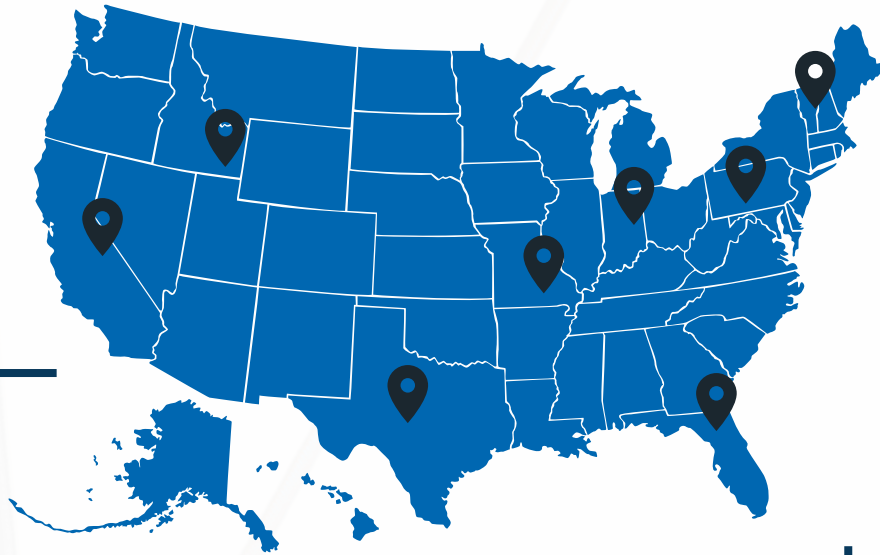


2700+

messages sent to policymakers

Connecting innovation to hope

In 2024, more than **1,000 individuals** participated in a patient survey to gather data for the **2024 National Immunoglobulin (Ig) Treatment Experiences and Preferences Survey**.



01

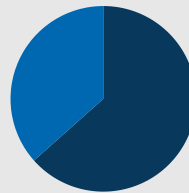
Who participated?



Patient: 93% Adult
Race: 91% "White"
Sex: 85% Female
Average age: 56
Diagnosis: CVID

02

Treatment mode:



SCIG: 63.3%
IVIG: 36.5%
IM: 0%

This survey aims to learn more about the treatment and care of patients with these conditions. Co-developed with immunologists who are experts in primary immunodeficiency, the 5th National Ig Survey specifically focuses on patients' experiences with intravenous immunoglobulin (IVIG), subcutaneous immunoglobulin (SCIG), and intramuscular immunoglobulin (IM) replacement therapy.

Results will be available soon.



\$159,500

awarded to **four** research grants related to:

Precision approaches for pediatric Evans syndrome

Dr. Emily Harris is conducting groundbreaking research on Evans syndrome, a rare autoimmune condition often linked to underlying PI in children. Her team has identified a specific T cell type, cTfm1/17, that may drive the disease and help distinguish it from other autoimmune disorders. The research aims to develop diagnostic and prognostic tools for earlier detection and more precise treatment, moving beyond the current "watch and wait" approach. By focusing on these T cells, Harris hopes to enable targeted therapies that avoid broad immune suppression and transform care for Evans syndrome patients.

Development of diagnostic screening tool for children with HLH

Dr. Lauren Meyer, a pediatric hematology/oncology fellow at Seattle Children's, is developing a better diagnostic screening tool for hemophagocytic lymphohistiocytosis (HLH), a life-threatening inflammatory disease often mistaken for more common conditions. Building on prior work identifying three key lab tests: ferritin, fibrinogen, and triglycerides, she will define cutoff values and apply data modeling to a larger patient group. The goal is to enable earlier HLH diagnosis and treatment, ultimately improving outcomes.

Machine learning for Inborn Errors of Immunity pattern recognition

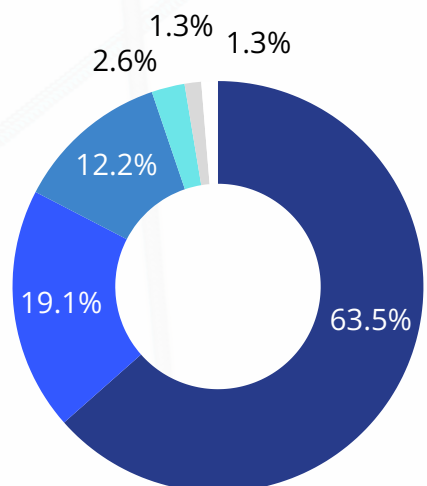
Dr. Alexandra Martinson, a pediatrics research resident at Children's National, is pioneering a machine learning approach to PI diagnosis that avoids traditional expert bias. By applying unsupervised clustering to millions of anonymized health records from over 100 medical centers, her research uncovers new diagnostic patterns. Martinson aims to identify features unique to PI subsets and integrate them into the SPIRIT Analyzer tool for earlier, more systematic detection of inborn errors of immunity.

CRISPR editing to assess JAK3 VUSs from patients with likely PID/PIRD

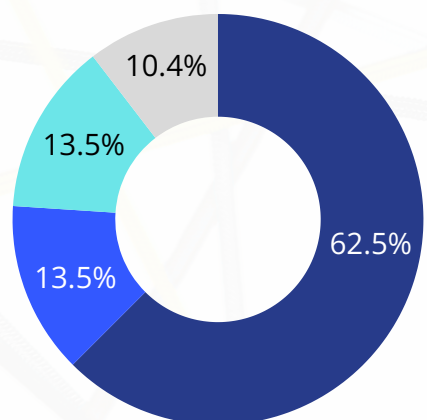
Dr. David Nguyen is investigating whether single-copy variants in the JAK3 gene cause immune dysregulation in four patients, suggesting a novel form of primary immunodeficiency. Unlike typical SCID cases, these patients have mutations in only one gene copy. Using CRISPR gene editing, Nguyen will recreate the variants in donor immune cells to study their effects. His research aims to provide molecular diagnoses, develop new diagnostic tools for hard-to-classify PIs, and potentially pave the way for CRISPR-based therapies.

2024 Financials

Connecting resources to results



- Contributions and grants
- Special events
- Net investment income
- In-kind contributions
- Other income
- Government grants and other contract revenue



- Services to patients and families
- Marketing and fundraising
- Administration and finance
- Medical and scientific

REVENUE

FOR THE YEAR ENDING DECEMBER 31, 2024

Contributions and grants	\$7,336,685
Special events	\$2,213,762
Net investment income	\$1,480,847
In-kind contributions	\$302,129
Other income	\$15,870
Government grants and other contract revenue	\$15,072
Total	\$11,364,365

FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2024

Services to patients and families	\$6,062,654
Marketing and fundraising	\$1,374,601
Administration and finance	\$1,356,925
Medical and scientific	\$1,047,079
Total	\$9,841,259

STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2024

	PROGRAM SERVICES		SUPPORTING SERVICES		
	Medical & scientific	Patients & families	Admin & finance	Marketing & fundraising	Total
Salaries	\$373,421	\$2,096,004	\$889,772	\$536,066	\$3,895,263
Employee benefits	\$53,769	\$299,596	\$173,792	\$71,156	\$598,313
Payroll taxes, etc.	\$28,043	\$160,329	\$63,904	\$41,913	\$294,189
Total	\$455,233	\$2,555,929	\$1,127,468	\$649,135	\$4,787,765
Advertising	\$35,000	\$49,512	\$3,146	\$308,431	\$396,089
Awards and grants	\$228,661	\$3,275	-	-	\$231,936
Bank fees	\$20,382	\$95,533	\$30,124	\$31,241	\$177,280
Consulting fees	\$122,129	\$760,644	\$24,043	\$43,527	\$950,343
Dues & subscriptions	\$14,775	\$143,536	\$35,050	\$24,968	\$218,329
Insurance	\$12,018	\$17,386	\$5,585	\$4,621	\$39,610
Occupancy	\$12,497	\$57,497	\$20,194	\$13,301	\$103,489
Other expenses	\$12,520	\$22,528	\$7,638	\$3,957	\$46,643
Office expenses	\$6,816	\$54,818	\$36,008	\$17,361	\$115,003
Postage and shipping	\$5,205	\$43,158	\$1,457	\$36,137	\$85,957
Printing and copying	\$1,181	\$50,101	\$312	\$46,419	\$98,013
Training, conference, conventions, and meetings	\$95,729	\$1,800,521	\$21,457	\$155,790	\$2,073,497
Transportation/travel	\$11,036	\$313,677	\$23,902	\$24,922	\$373,537
Total	\$1,033,182	\$5,968,115	\$1,336,384	\$1,359,810	\$9,697,491
Depreciation amortization	\$13,897	\$94,539	\$20,541	\$14,791	\$143,768
Grand total	\$1,047,079	\$6,062,654	\$1,356,925	\$1,374,601	\$9,841,259

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

FOR THE YEAR ENDING DECEMBER 31, 2024

	without donor restrictions	with donor restrictions	Total
PUBLIC SUPPORT AND REVENUE			
Public support & revenue			
Contributions & grants	\$6,511,185	\$825,500	\$7,336,685
In-kind contributions	\$302,129	-	\$302,129
Government grants & other contract revenue	\$15,072	-	\$15,072
Other income	\$15,870	-	\$15,870
Special events	\$2,213,762	-	\$2,213,762
Net investment income	\$1,480,847	-	\$1,480,847
Net assets released from restrictions	\$1,854,788	(\$1,854,788)	-
Total public support & revenue	\$12,393,653	(\$1,029,288)	\$11,364,365
EXPENSES AND LOSSES			
Program services			
Medical & scientific	\$1,047,079	-	\$1,047,079
Patients & families	\$6,062,654	-	\$6,062,654
Total program services	\$7,109,733	-	\$7,109,733
Supporting services			
Administration & finance	\$1,356,925	-	\$1,356,925
Marketing & fundraising	\$1,374,601	-	\$1,374,601
Total supporting services	\$2,731,526	-	\$2,731,526
Total expenses	\$9,841,259	-	\$9,841,259
Changes in net assets	\$2,552,394	(\$1,029,288)	\$1,523,106
Net assets, beginning of the year	\$14,001,757	\$1,914,992	\$15,916,749
Net assets, end of year	\$16,554,151	\$885,704	\$17,439,855

Volunteer leadership

IDF Board of Trustees

The IDF Board of Trustees brings together diverse expertise to provide organizational leadership and chart pathways for continued impact and growth.



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2024

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IDF sponsors and supporters

IDF sponsors and donors help build bridges to better understanding, care, and connection by making it possible to provide trusted educational materials and local programming for patients, families, and healthcare professionals. Their support helps shape a stronger future for the PI community. IDF greatly appreciates these steadfast supporters and all of our individual contributors for their commitment to our mission.

★ Top fundraisers

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👥 Local Walk for PI sponsor

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