Immune Deficiency Foundation

2023 ANNUAL REPORT

Advancing knowledge.
Inspiring hope.

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Our vision

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

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.

President's letter

As we reflect on the past year, I am filled with a profound sense of gratitude and inspiration. The Immune Deficiency Foundation (IDF) has made remarkable strides in advancing knowledge and inspiring hope for individuals living with primary immunodeficiency (PI) and other immune disorders.

Our unwavering commitment to supporting and empowering those affected by PI has been the driving force behind our achievements. In 2023, we had the privilege of directly impacting the lives of 30,320 individuals living with PI, providing them with invaluable resources, guidance, and a strong sense of community. However, our mission extends far beyond these numbers, as we strive to reach every one of the estimated 14 million Americans under the age of 65 affected by immune deficiencies.

Last year, we raised awareness, provided educational opportunities, and advocated for better access to healthcare. Our 2023 accomplishments are a testament to the tireless efforts of our small, but mighty 40-member staff, more than 500 volunteers, corporate sponsors, and thousands of supporters who raised more than $8.6 million in pursuit of a healthier day, every day, for every person with immune deficiency.

Our educational initiatives consisted of 64 sessions with more than 14,000 views, receiving a 4.7-star rating from attendees who found our events invaluable for understanding and managing PI. Our reimagined, streamlined and user-friendly website welcomed 822,098 visitors seeking information and guidance.

Dedicated to patient-centered research, we awarded $192,500 in grants to five groundbreaking projects, from understanding T cells in Schimke immune-osseous dysplasia to tracking gut microbiome changes after fecal transplants for CGD-AC treatment. Each of the five studies holds a potential for improving diagnosis, care, and quality of life.

Our ongoing advocacy efforts have yielded promising progress, contributing to proposed federal legislation to ban copay accumulators and efforts to restore a federal rule in D.C. that would ensure insurers apply copay assistance to deductibles and out-of-pocket maximums.

Looking ahead, our commitment remains steadfast: ensuring every person with an immune deficiency can access the care, support, and resources needed to live their healthiest lives. Together, we impact so many, empowering resilience and hope.

Jorey Berry
PRESIDENT & CEO

Our leadership team

The Immune Deficiency Foundation (IDF) is guided by a dynamic team who are passionate about improving the lives of individuals with primary immunodeficiency (PI). This dedicated group oversees and drives the strategic direction of the organization, ensuring that programs and initiatives align with the needs of the PI community.

In addition to President and CEO Jorey Berry, the leadership team is comprised of seasoned professionals who excel in their respective fields. From advocating for patient rights on Capitol Hill to cultivating a strong and engaged community, each leader brings a unique perspective and expertise to the table.

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Our impact
Advancing knowledge

Fostering knowledge and understanding lies at the core of the Immune Deficiency Foundation's mission. We hosted 64 educational sessions, both in-person and virtually. These interactive sessions provided a comprehensive exploration of primary immunodeficiency, equipping attendees with the knowledge and tools to better comprehend and manage their condition.

64
educational sessions

3,203
live participants

14,404
additional views on YouTube

Ask IDF

Our online website tool used for individuals to ask PI-related questions to help them along their healthcare journey.

Addressed more than **1,668** questions spanning more than 38+ topic areas.

Each question was addressed in **72** hours or less.

Notably, **treatment-related inquiries** emerged as the most prevalent concern, underscoring a commitment to empowering individuals with the information they need to navigate their healthcare journey with confidence.

Medical professionals

need educational resources, just as those living with PI do. By raising awareness and knowledge among healthcare providers, we can improve early identification and timely diagnosis of PI, ultimately leading to better outcomes for patients.

Consulted with approximately **1,395** medical professionals at **9** different medical conferences. Another **1,800** healthcare providers attended IDF-led presentations.

Published **8** specialty-specific flyers for healthcare professionals to learn the most relevant signs and symptoms of PI related to their field of study.

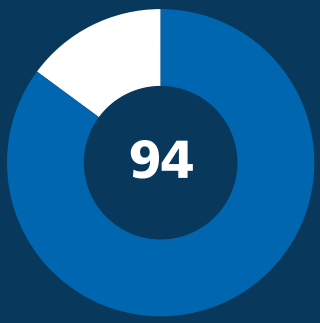
636 clinicians located in **47** different states and Puerto Rico make up our Clinician Finder, a tool patients can use to find a medical professional near them.

A **56%** increase in physician consults compared to 2022 through the Consulting Immunologist program.

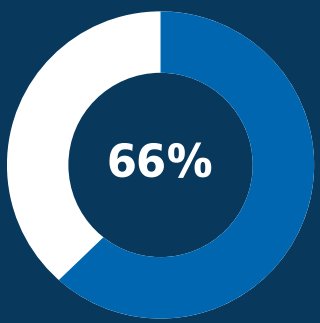
Project Echo

IDF partnered with Project ECHO at Penn State College of Medicine and presented a virtual clinician education series on understanding primary immunodeficiencies (PI). The series consisted of ten sessions aimed at helping providers recognize the signs of PI and take appropriate, timely steps for diagnosis. It provided an overview of up-to-date, evidence-based treatment recommendations and guidelines.

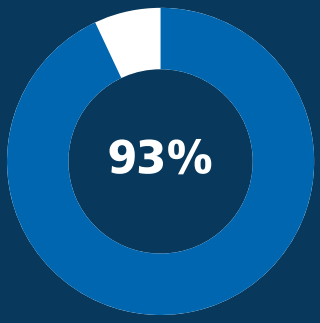
> **I have an allergy and immunology clinic in Dubai and Pakistan and I feel this will greatly help manage my patients.**
>
> - Project Echo participant



Active participants, 80 providers from the U.S.



Plan to make changes in their practice



Increased knowledge

Would recommend Project ECHO to a colleague

Connecting communities

Walk for PI

an in-person opportunity for fundraising and friendraising!

2,000
participants

8
cities (plus a virtual walk)

218
teams

$917,741
raised

Just because a disease is rare doesn't mean a person has to feel alone. Whether a person prefers in-person connections or virtual meet-ups, we offered many opportunities for connection in 2023.

Get Connected Groups

281 virtual Get Connected Group meetings were held with more than **1,600** participants.

Peer support

41 trained volunteers participated in our Peer Support Program. This provided **45** individuals one-on-one support and guidance during their journey with primary immunodeficiency.

Voices of change: IDF Podcast's journey through health equity and the undiagnosed

In 2023, we revamped our podcast, rebranding it as the IDF Podcast, a platform bringing together connection and shared experiences. We launched two compelling series. The first, Bold Conversations, is a five-part series hosted by Dr. Nicole Rochester that explores the realities of health equity, educating listeners and combating medical injustice. The second series, Undiagnosed, showcases the true stories of the long and arduous journeys individuals face before receiving a primary immunodeficiency (PI) diagnosis.

This rebranded podcast served as a powerful medium, fostering understanding, empathy, and a sense of community. Through **18** thought-provoking episodes, the IDF Podcast garnered an impressive **17,127** listens, amplifying voices and creating a resonating impact on a global scale.

Social media outreach growth

- **5.6%**
- **11%**
- **27%**
- **36%**

Through the Immune Deficiency Foundation (IDF), I learned that everyone has their own story to share; that's what makes this community so beautiful. We all have that one common enemy, and though it all affects us differently, we are able to find common struggles and experiences with each other, which makes us closer as a community.

- Ella, living with severe combined immunodeficiency (SCID)

Addressing BARRIERS to treatment

Copay assistance helps offset medication costs for vulnerable patients like those living with primary immunodeficiency. However, copay accumulator programs prevent this aid from counting toward insurance deductibles or out-of-pocket maximums. This can significantly increase patients' annual costs. Insurance providers argue these programs encourage brand-name drug use, but most copay assistance is for drugs without generic alternatives like immunoglobulin (Ig) therapy.

The Immune Deficiency Foundation (IDF) is closely monitoring legislation addressing copay accumulator programs at the federal and state levels. **Twenty-one** states, plus the District of Columbia and Puerto Rico, have banned copay accumulators. With support from IDF legislation was reintroduced to ban copay accumulators federally by a bill called H.R.830 in the U.S. House of Representatives. The District of Columbia restored a federal rule banning most copay accumulators. Insurers are now required to apply copay assistance to patient deductibles and out-of-pocket maximums in that region.

IDF is continuing to push for legislative solutions to permanently ban these policies and protect patient interests.

52
letters signed and sent to legislators

191
legislative meetings

806
individuals participated in IDF email alerts

in support of advocating for healthcare access & equity for patients with rare and chronic conditions.

Maryland Senate Bill 188 (SB 188) established the Maryland Rare Disease Advisory Council (RDAC).

Bipartisan push for Ig therapy coverage

On April 28, 2023, Representatives Doris Matsui (D - CA) and Adrian Smith (R - NE) introduced H.R.3017, which 'carves out' the cost of immunoglobulin replacement (Ig) therapy from the daily Medicare per diem paid to skilled nursing facilities and allows those facilities to separately bill Medicare for that treatment.

Inspiring hope with science

In 2023, more than **1,100** individuals participated in **two** patient surveys to gather data on the PI patient experience since no federally funded health surveys in the United States collect information on PI.

Who participated?

Age

Patients ranged in age from **5-91**

Gender

0.1% were intersex at birth.

13.9% male

86% female

Diagnoses

The most reported.

- **62%** Common variable immune deficiency (CVID)
- **10%** Hypogammaglobulinemia
- **9%** Specific antibody deficiency (SAD)

The results

92% experienced repeated, unusual, or serious infections leading to testing for PI/IEI.

Consistently found **ALLERGIES AND ASTHMA** to be two of the most reported co-occurring conditions in individuals with PI, suggesting that these diagnoses are even more common in the PI population.

42% reported more than one permanent impairment prior to diagnosis, the most common impairment being in the lungs.

Respondents with a prior autoimmune diagnosis were more likely to have a time to diagnosis of **10 YEARS OR MORE**

SINUSITIS AND BRONCHITIS were the most common infections seen in those living with PI before and after diagnosis.

For the full report. Click here or scan the QR code.

Improving treatment, health, and disease management of those living with PI

$192,500 awarded to five research grants in topics related to:

GENE EDITING IN X-LINKED AGAMMAGLOBULINEMIA

Dr. Donald Kohn's research focuses on developing a more precise gene therapy approach for X-linked agammaglobulinemia (XLA), a rare genetic disorder. Unlike his previous work with random gene insertion, Kohn is now using CRISPR/Cas9 gene editing to insert a functional Bruton's tyrosine kinase (BTK) gene at a specific location in patients' DNA. This method aims to maintain the gene's natural expression control, avoiding potential cancer risks associated with random insertion. Kohn's lab has shown promising results in human cell lines and non-XLA stem cells. With his awarded IDF grant, he plans to test this approach in XLA patients' stem cells and in mouse models, hoping to advance to clinical trials within a few years. Kohn also considers alternative models for bringing such therapies to patients, given recent challenges in the gene therapy commercial market.

UNDERSTANDING T CELLS IN SCHIMKE IMMUNE-OSSEOUS DYSPLASIA (SIOD)

Awardee, Dr. Benjamin Soloman shares, "This IDF award supports work to develop new statistical and computational methods capable of revealing the biology of even the rarest immune deficiencies, leading to new avenues of diagnosis and treatment."

FINDING ANSWERS FOR THOSE WITH SUSPECTED PI WHO DO NOT HAVE A GENETIC DIAGNOSIS

Dr. Xiao Peng plans to use specialized technology called optical genetic mapping (OGM) followed by targeted long-read sequencing (LRS). OGM and LRS will help her look for duplications of large regions of DNA, large insertions and deletions, and places where a section of DNA has been flipped around. They will also allow her to look at regions of human DNA that can't usually be analyzed with SRS data. Peng predicted that her approach "will help more undiagnosed patients receive research-based sequencing towards the goal of getting them to molecular diagnosis."

T CELL MARKERS THAT CORRELATE WITH X-LINKED HYPER IGM SYNDROME

Dr. Junghee Jenny Shin at Yale University is researching CD40 ligand deficiency (CD40LD), aiming to predict symptom severity based on T cell properties. CD40LD, caused by genetic variants affecting the CD40L protein, results in antibody production issues and varied clinical outcomes. Shin's study will analyze gene expression and protein production in T cells of CD40LD patients compared to healthy individuals. By linking genetic variants to disease severity and T cell characteristics, she hopes to develop more precise treatment strategies to improve infection prevention, reduce cancer risk, and enhance survival rates for CD40LD patients.

TRACKING GUT MICROBIOME CHANGES AFTER FECAL MICROBIOME TRANSPLANT (FMT) TO TREAT CGD-AC

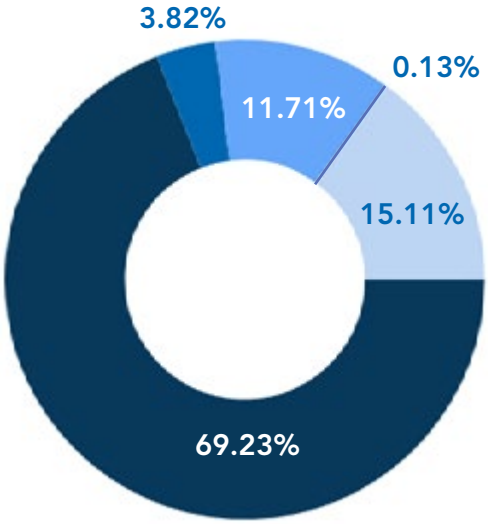
Dr. Brynn O'Laughlin's research may help "in the design of live biotherapeutic products for the treatment of CGD-AC if the effective components of FMT are uncovered." Such a product, which might consist of a specific, precise mix of microorganisms, could be more reliably manufactured than the preparations that are currently used in FMT.

2023 Financials

REVENUE

FOR THE YEAR ENDING DECEMBER 31, 2023.

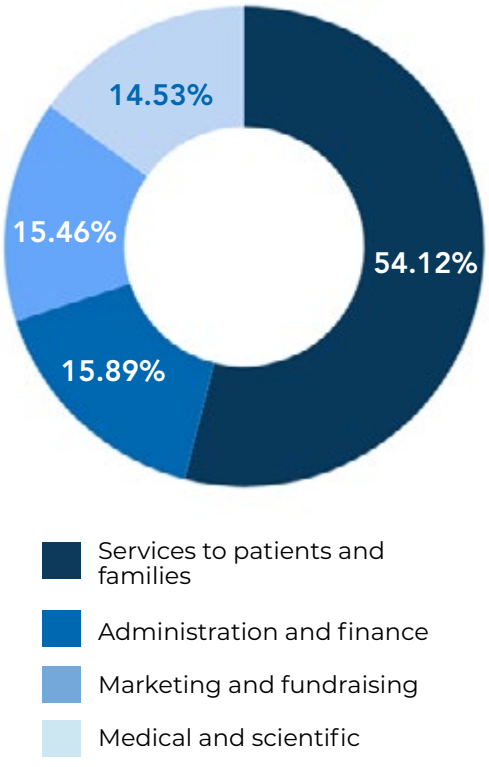
Contributions and grants	$7,070,854
Government grants and other contract revenue	$389,872
Special events	$1,196,453
Net investment income	$1,543,192
Other income	$13,090
Total	$10,213,461



FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2023.

Services to patients and families	$3,971,854
Administration and finance	$1,165,747
Marketing and fundraising	$1,134,466
Medical and scientific	$1,066,655
Total	$7,338,722



STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2023.

	PROGRAM SERVICES		SUPPORTING SERVICES		
	Medical & scientific	Services to patients & families	Admin & finance	Marketing & fundraising	Total
Salaries	$362,080	$1,931,360	$798,810	$521,951	$3,614,201
Employee benefits	$48,446	$278,403	$132,519	$70,333	$529,701
Payroll taxes, etc.	$26,964	$146,937	$59,537	$40,591	$274,029
Total	$437,490	$2,356,700	$990,866	$632,875	$4,417,931
Advertising	$44	$9,850	$0	$17,504	$27,398
Awards & grants	$217,500	$250	$0	$0	$217,750
Bank fees	$2,976	$5,763	$8,821	$97,279	$114,839
Consulting fees	$177,656	$838,723	$22,511	$55,742	$1,094,632
Dues & subscriptions	$17,038	$115,409	$21,723	$32,811	$186,981
Insurance	$11,732	$14,697	$4,987	$11,251	$37,680
Interest	$0	$0	$64	$0	$64
Occupancy	$15,128	$51,080	$21,461	$15,314	$102,983
Office expenses	$12,363	$65,421	$24,934	$16,099	$118,817
Other expenses	$2,982	$26,156	$6,411	$19,668	$55,217
Postage and shipping	$22,935	$32,455	$0	$35,406	$90,796
Printing and copying	$19,369	$54,362	$447	$41,592	$115,770
Training, conference, conventions and meetings	$88,248	$253,204	$20,506	$117,517	$479,475
Transportation/travel	$17,036	$61,940	$7,467	$23,218	$109,661
Total	$1,042,497	$3,886,010	$1,131,475	$1,110,012	$7,169,994
Depreciation amortization	$24,158	$85,844	$34,272	$24,454	$168,728
Grand totals	$1,066,655	$3,971,854	$1,165,747	$1,134,466	$7,338,722

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

FOR THE YEAR ENDING DECEMBER 31, 2023.

	without donor restrictions	with donor restrictions	Total
PUBLIC SUPPORT AND REVENUE			
Public support & revenue			
Contributions & grants	$5,280,018	$1,790,836	$7,070,854
Government grants & other contract revenue	$389,872	$0	$389,872
Other income	$13,090	$0	$13,090
Special events	$1,196,453	$0	$1,196,453
Net investment income	$1,543,192		$1,543,192
Net assets released from restrictions	$1,195,964	($1,195,964)	$0
Total public support and revenue	$9,618,589	$594,872	$10,213,461
EXPENSES AND LOSSES			
Program services			
Medical & scientific	$1,066,655	$0	$1,066,655
Services to patients & families	$3,971,854	$0	$3,971,854
Total program services	$5,038,509	$0	$5,038,509
Supporting services			
Administration & finance	$1,165,747	$0	$1,165,747
Marketing & fundraising	$1,134,466	$0	$1,134,466
Total supporting services	$2,300,213	$0	$2,300,213
Total expenses	$7,338,722	$0	$7,338,722
Change in net assets	$2,279,867	$594,872	$2,874,739
Net assets, beginning of the year	$11,721,890	$1,320,120	$13,042,010
Net assets, end of year	$14,001,757	$1,914,992	$15,916,749

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Corporate partners ensure IDF can continue to provide educational materials and local programming to patients and families, as well as healthcare professionals. IDF greatly appreciates these steadfast supporters and all of our individual contributors for their commitment to our mission.

$500,000 and above

CSL Behring

Grifols

Takeda

$200,000 - $499,999

Amgen (formerly Horizon Therapeutics)

$100,000 - $199,999

AstraZeneca

Chiesi Global Rare Disease

Pharming

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Sumitomo (formerly Enzyvant)

X4 Pharmaceuticals

$50,000 - $99,999

Accredo

ADMA Biologics

CVS Health

Kedrion BioPharma (formerly Bio Product Laboratory)

Octapharma

Merck

$25,000 and below

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Chiesi Global Rare Disease

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$100,000 - $299,999

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Monthly donors (cont.)

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Valerie Vogt

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Visionaries who ignited a movement, inspiring hundreds to contribute and drive real change. Their leadership sparked waves of generosity, and we're profoundly grateful for their impact.

Connor Colquhoun (CdawgVA)
Ironmouse
Sadie Smiles
Team Cream
Team CuKo
The Burdzinski family
The Taters
VShojo

Thank you for your support!

The Immune Deficiency Foundation makes every effort to ensure the accuracy of donor and fundraiser lists. We extend our deepest regrets to any donor who may have been inadvertently omitted from this report. If you have a concern or correction, please contact us at 410-321-6647 or email us at development@primaryimmune.org.

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