2021 ANNUAL REPORT

BUILDING OUR FUTURE

Immune Deficiency Foundation

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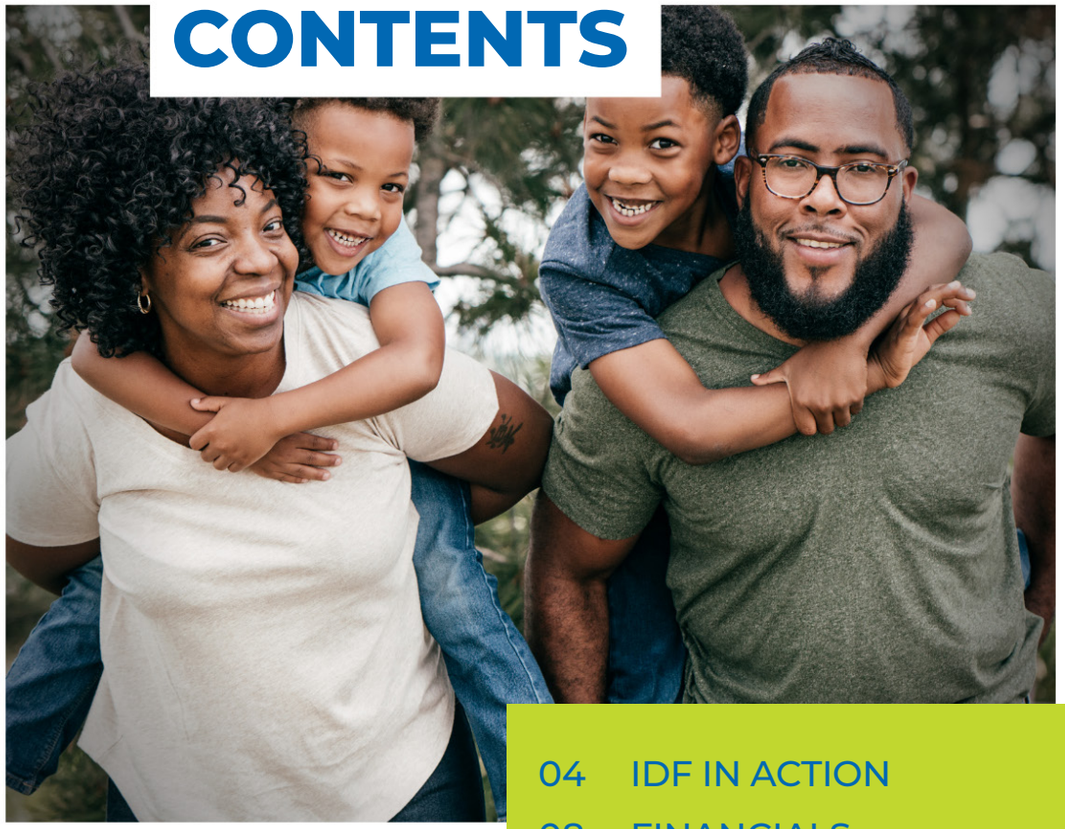


OUR MISSION

The Immune Deficiency Foundation (IDF) improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency (PI) through fostering a community empowered by advocacy, education, and research.

OUR VISION

IDF seeks to ensure that everyone in the U.S. affected by PI has a fully informed understanding of the PI diagnosis that affects them, all available treatment options, the expected standard of care, and all of their opportunities for connection and support within the PI community.

Immune Deficiency Foundation

a year's overview

WHERE WE ARE. WHERE WE'RE GOING.

A letter to the PI community from Tracy Shaw, 2022 Board Chair.

If 2020 was the year of the pivot, then 2021 was the year we began to build our future by strengthening our foundation and fortifying IDF's mission. It was the second year of providing completely virtual programming to the community and while national trends indicated that people were "zoomed out", this community (you!) participated at even greater rates than the year before. We saw a 39% increase in educational sessions, a 45% increase in participation in Advocacy Day, and hosted the largest PI conference in our history with 2,500 participants. While we're ready and excited to begin to meet each other in person in 2022, my commitment to you is that we will continue to provide robust and engaging online opportunities to reach those who are unable to attend in person.

There's no denying that the COVID-19 pandemic has changed the way we do business. In 2019, most of our employees were based in Maryland, with just three working remotely. We're now a distributed workforce, with employees working in twelve states. With that change came an investment in technology and infrastructure to ensure that we can work with as much agility as possible. That means results matter more than ever. Our decisions are informed by data and feedback from you, our supporters.

There is so much that we accomplished in 2021 of which I'm proud, not the least of which are the initiatives that have become national models for awareness and engagement: SCID Compass, a large-scale education program for families facing a SCID diagnosis has been translated into eleven languages and is used as a resource for rare disease advocates from all over the world. Plasma Hero (launched in 2020), grew to become the go-to information source for those who wish to donate plasma. Finally, the Immunocompromised Collaborative provided a voice for the estimated nine million Americans who are most at risk of health complications during the global pandemic.

Our strategic priorities continued to guide our work throughout 2021, with our dedication to reducing time to diagnosis including appropriate treatment remaining paramount. That means being findable for those who are still undiagnosed as much as helping find the undiagnosed by reaching out to clinicians who may not know there is a zebra in their practice. The IDF's public policy and advocacy team, too, are guided by our commitment to improving access and reducing health disparities. Embracing diversity while growing the IDF community remains important to us for as many reasons as all of you. This is important because we're stronger and healthier as a community when we are stronger and healthier as individuals.

As one last note, I'm proud to say that we ended the year on a high note – announcing our new President & CEO, Jorey Berry. Jorey brings a proven track record of success and a deep understanding of organizational change and growth. The future that we're building – together – is an exciting one. And I'm thrilled that each of you are with us on the journey.

Sincerley,

Tracy Shaw

Tracy Shaw

IDF IN ACTION

EDUCATION

Primary immunodeficiencies (PI) consist of more than 450 rare disorders. Our priority is to offer accurate, unbiased information so patients and caregivers can better understand their diagnosis and make informed decisions regarding their health.

A **39% increase** of educational sessions compared to 2020.

6,177 individuals participated in live educational sessions.

Educational sessions received **62,393 post-event views** on YouTube.

PROVIDING CLARITY

IDF **addressed 5,654 information requests** asked by the PI community.

Proudly distributed 119,691 educational materials at no cost to patients and families.

NEW RESOURCE FOR THOSE LIVING WITH SCID

Based on surveys conducted in the medical community, IDF identified the need for a **SCID provider fact sheet**. The fact sheet informs pediatricians and primary care providers about SCID, and provides them with guidelines on how to communicate a diagnosis to a family. The two-page fact sheet defines SCID, summarizes the causes of SCID, and describes how newborn screening identifies a potential diagnosis. Most importantly, the fact sheet outlines a list of considerations related to handling an abnormal newborn screening.

To download the form, please scan the QR code

PROGRAMS FOR HEALTHCARE PROFESSIONALS

to encourage continuous education

Educational Presentations
IDF developed three webinars for healthcare professionals to better identify and treat individuals living with PI.

Clinician Finder
An IDF tool listing 768 healthcare professionals connecting patients and providers.

Consulting Immunologist Program
A physician-to-physician service that offering 50 clinicians a free second opinion from a national network of renowned immunologists.

CONNECTION & SUPPORT

We believe that by surrounding yourself with a community of people who support you, you can thrive. Our programs are meant to connect, engage, and empower families to live longer, stronger, healthier lives.

Get Connected Groups
More than 1,300 individuals connected during 216 meetings hosted across the country.

PEER SUPPORT
614 individuals volunteered to support those living with PI. Of these, 107 individuals volunteered specifically to provide peer support.

Walk for PI
1,010 people participated in 33 virtual walks across the U.S. helping to remind those living with PI that they are not alone. They raised awareness and more than $667,000!

When I was diagnosed with PI 17 years ago, I thought I would never find someone like me with the same struggles and experiences. IDF has fostered a sense of belonging to a larger community.

- Madi Holland,
living with Hypogammaglobulinemia

PUBLIC POLICY

We've been on the front lines helping maintain forward-thinking health policy changes that were implemented for the PI community during the pandemic.

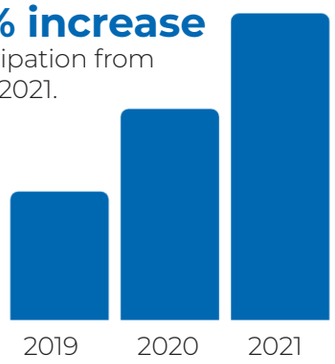
The Immune Deficiency Foundation developed a relationship with the CDC COVID-19 Response Team, allowing IDF to provide input for the CDC website and CDC guidance pages related to the immunocompromised. Additionally, we recognized the importance of home-based infusions for members of the PI community. This is why IDF ensured Medicare IVIG Home infusion benefit was extended through 2021 and supported telehealth and home infusion flexibilities adopted as part of the COVID-19 public health emergency.

IDF ADVOCACY DAY

385 patients and families participated in **191 virtual** meeting with Congress.

A **45% increase** in participation from 2020 to 2021.

An additional **194 individuals** utilized IDF's **Action Alert system** to send messages to Congress on the day of the event.



FIGHTING UNFAIR CO-PAY ACCUMULATORS AND **SUPPORTING THE HELP COPAYS ACT**

In 2021, IDF worked to ban co-pay accumulators, which block co-pay assistance from being counted toward deductibles or out-of-pocket maximums, at both the state and the federal level. We identified that this issue must be tackled at both levels because some insurance plans are regulated by the federal government, while others are regulated by state governments. At the state level, we have successfully helped pass legislation that bans co-pay accumulators in 13 states (Arizona, Arkansas, Connecticut, Georgia, Illinois, Kentucky, Louisiana, North Carolina, Oklahoma, Tennessee, Virginia, Washington and West Virginia) and Puerto Rico. IDF is expanding efforts in 2022 to make #AllCopaysCount at the federal level too!

RESEARCH

Leading by example. We are dedicated to research that will help improve the quality of life for generations to come.

In 2021, **nine manuscripts** were written and published in peer-reviewed scientific journals. **Seven of the abstracts in the manuscripts used United States Immunodeficiency Network (USIDNET) registry data** and were accepted and featured at national medical conferences across the world.

WHITE PAPER CHALLENGE

As an organization, we sought to address new ideas related to IDF's goals of the persistent challenge to achieve earlier diagnosis among those living with PI and expanding and diversifying our community.

In an effort to seek new solutions, we sponsored a White Paper Challenge and invited submissions to address:

- **Innovative practices to expand PI awareness in communities of color**
- **Methods to increase equity in clinical trials**
- **Novel approaches to shortening the time between diagnosis and treatment.**

The challenge went out in 2021 to all individuals, institutions, schools, and researchers. Three different awards of $10,000 were rewarded (in early 2022).

2021 FINANCIALS

REVENUE

FOR THE YEAR ENDING DECEMBER 31, 2021.

Corporate* Sponsorships and Grants (includes walk funding)	$5,375,303	52%
Contributions - Individuals	$662,368	6%
Government Grants	$2,167,844	21%
Investment Income	$1,267,100	12%
Special Events - Walks - Individuals (Sponsorships reflected above)	$171,060	2%
Special Events - Other	$235,910	2%
Other income (including PPP)	$540,483	5%
Total	$10,420,068	100%

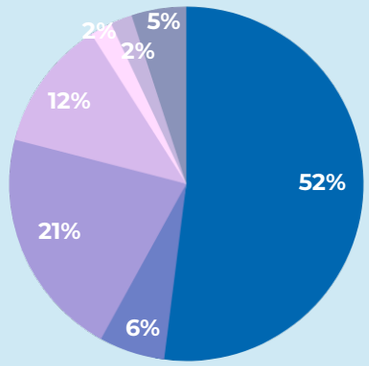
FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2021.

Medical and Scientific	$757,081	9%
Services to Patients and Families	$5,205,460	65%
Business Operations	$1,268,203	16%
Marketing and Fundraising	$792,871	10%
Total	$8,023,615	100%

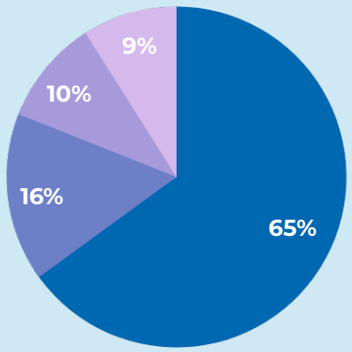
**This consists of contributions for programs, patient education, and events from pharmaceutical, biotechnology and medical device companies.*

REVENUE



- Corporate* Sponsorships and Grants (includes walk funding)
- Contributions - Individuals
- Government Grants
- Investment Income
- Special Events - Walks - Individuals (reflected above)
- Special Events - Other
- Other income (including PPP)

EXPENSES



- Services to Patients & Families
- Business Operations
- Marketing & Fundraising
- Medical & Scientific

STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2021.

	PROGRAM SERVICES		SUPPORTING SERVICES		
	Medical & Scientific	Services to Patients & Families	Admin & Finance	Marketing & Fundraising	Total
Salaries	$308,302	$1,603,661	$620,405	$399,649	$2,932,097
Employee Benefits	$37,535	$230,501	$71,725	$54,619	$394,380
Payroll Taxes, etc.	$23,366	$129,203	$51,538	$32,054	$236,161
Total	$369,283	$1,963,365	$743,668	$486,322	$3,562,638
Advertising	$22,498	$110,233	$0	$3,648	$136,379
Awards & Grants	$0	$69,977	$0	$0	$69,977
Bank Fees	$3,551	$33,108	$15,159	$35,286	$87,104
Consulting Fees	$226,059	$2,244,972	$179,697	$83,867	$2,734,595
Dues & Subscriptions	$55,413	$173,288	$15,797	$7,122	$251,620
Insurance	$7,821	$19,794	$9,051	$4,255	$40,921
Interest	$0	$0	$4,641	$0	$4,641
Occupancy	$18,740	$174,725	$61,226	$26,973	$281,664
Permits & License	$0	$0	$766	$10,424	$11,190
Postage & Shipping	$1,782	$46,229	$2,555	$40,455	$91,021
Professional Fees	$1,615	$11,432	$5,188	$1,749	$19,984
Rental & Maintenance of Equipment	$4,131	$25,209	$9,698	$3,056	$42,094
Repairs & Maintenance	$94	$878	$402	$136	$1,510
Staff Development	$450	$46,295	$129,313	$0	$176,058
Supplies	$1,890	$96,733	$44,241	$55,269	$198,133
Telephone	$15,819	$45,595	$13,105	$6,754	$81,273
Training, conference, conventions & meetings	$17,636	$74,729	$0	$16,276	$108,641
Transportation/Travel	$3,012	$952	$2,587	$790	$7,341
Total	$749,794	$5,137,514	$1,237,094	$782,382	$7,906,784
Depreciation Amortization	$7,287	$67,946	$31,109	$10,489	$116,831
Grand Totals	$757,081	$5,205,460	$1,268,203	$792,871	$8,023,615

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

FOR THE YEAR ENDING DECEMBER 31, 2021.

	without donor restrictions	with donor restrictions	Total
PUBLIC SUPPORT AND REVENUE			
Public Support & Revenue			
Contributions & Grants	$5,627,500	$410,171	$6,037,671
Government Grants & Other Contract Revenue	$2,167,844	$0	$2,167,844
Investment Income, Net	$1,267,100	$0	$1,267,100
Other Income	$540,483	$0	$540,483
Special Events	$406,970	$0	$406,970
Net Assets Released from Restrictions	$567,440	($567,440)	$0
Total Public Support and Revenue	$10,577,337	($157,269)	$10,420,068
EXPENSES			
Program Services			
Medical & Scientific	$757,081	$0	$757,081
Services to Patients & Families	$5,205,460	$0	$5,205,460
Total Program Services	$5,962,541	$0	$5,962,541
Supporting Services			
Administration & Finance	$1,268,203	$0	$1,268,203
Marketing & Fundraising	$792,871	$0	$792,871
Total Supporting Services	$2,061,074	$0	$2,061,074
Total Expenses	$8,023,615	$0	$8,023,615
Change in Net Assets	$2,553,722	($157,269)	$2,396,453
Net Assets, Beginning of the Year	$10,795,683	$650,315	$11,445,998
Net Assets, End of Year	$13,349,405	$493,046	$13,842,451

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EXPANDING OUR LEADERSHIP

JOREY BERRY ANNOUNCED AS PRESIDENT & CEO


JOREY L. BERRY

The Immune Deficiency Foundation (IDF) Board of Trustees announced Jorey Berry as the new President and Chief Executive Officer (CEO) of the organization after a nationwide search. She leads the IDF team (who reside in 13 different states) from her home in Fredericksburg, Texas.

Jorey brings a deep understanding of nonprofit management and a track record of demonstrated executive-level success to her new role leading IDF. For more than two decades, she held key roles in operations, advocacy, culture change, revenue, internal communications, and volunteer development during a 20-year tenure with the March of Dimes. Most recently, she served as Vice President of Change Management for the organization.

Berry holds a B.A. in English with a minor in Psychology from Texas A&M University and began her career as an English teacher. She then held several local and state advocacy positions before joining March of Dimes.

"It's an honor to be leading this internationally-recognized health organization with a legacy of accomplishment and service to people with PI," said Jorey. "I am eager to begin working alongside the passionate team of professionals to further advance IDF's advocacy, education, and research initiatives."

2021 CORE SERVICE PROGRAM

Because primary immunodeficiencies are rare, chronic conditions, program continuity is one of the most important aspects of the services provided by IDF. Because of the Core Service Program, IDF is able to provide educational materials and local programming to patients, families, and healthcare professionals free of charge. IDF greatly appreciates these supporters and all others who make our mission possible.

IDF Core Service Leaders

CSL Behring

Grifols

Takeda

IDF Core Service Supporter

Horizon Therapeutics

IDF Core Service Sustainer

Accredo Healthcare

Octapharma

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IDF WALK FOR PRIMARY IMMUNODEFICIENCY

An initiative of the Immune Deficiency Foundation

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Thank you to the following organizations and individuals for supporting IDF!

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$100,000 - $499,999

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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 800-296-4433 or email us at development@primaryimmune.org.

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