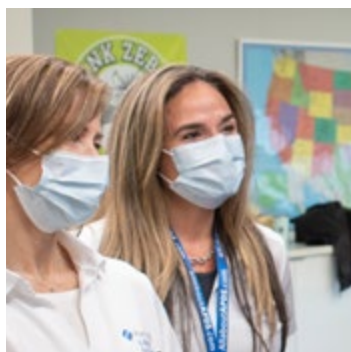


# Moving forward together.



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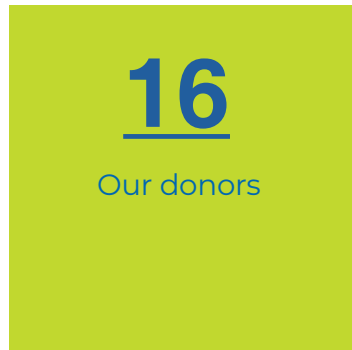
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# Our mission

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.



# Our values

transparency  
collaboration  
forward-thinking stakeholder compassion  
inclusion innovation  
making data-driven  
constituent impact integrity accountability  
commitment leadership trust  
decision  
promise



# Letter from our President & CEO



*“Our community may be rare, but our vision is bold.”*

**Jorey Berry**

*President & CEO*

## The magic of working together

When I began my role as CEO of the Immune Deficiency Foundation (at the very start of 2022), I sent each member of my team a copy of one of my favorite books: “Together is Better,” written by Simon Sinek. If you’ve never read the book, it’s a series of illustrations commonly referred to as a little book of inspiration. This book was, for lack of better words, kind to me at a time when I needed kindness. And I wanted to share that message with the new team I’d be leading and the new community I’d be meeting and representing.

What I didn’t know is how much this little book—and the belief that we can do more together than we can alone – guided our work for the year. So many messages in that little book of inspiration took on new meaning for me.

**Always plan for the fact that no plan will go according to plan.** It is no surprise that 2022 was a year of uncertainty for every member of the PI community. Going back to in-person events was a risky endeavor, but we needed to test what the community wanted and needed. We did our best to offer hybrid options, put strict safety protocols in place, and listen to each of you as we moved forward. While there were always lessons learned, I’m proud that we held fast to protect patient safety, even when it wasn’t easy or convenient.

**The best way to find out if it works is to do it.** During the year, we hosted a robust virtual Advocacy Day that became the largest in our history. And we moved our Walk for PI events to family-friendly, centrally located locations that helped to raise awareness and interest in the event. The Immunocompromised Collaborative expanded its work, helping to give a voice to those who had been left behind during the pandemic.

**To go fast, go alone. To go far, go together.** You’ll see in this report that almost every program experienced growth in 2022. And that’s because members of the PI community joined us by helping to grow our Get Connected Groups, fundraising teams, volunteer pool, educational offerings, and so much more. We all know that the journey to diagnosis is often long, difficult, and just the beginning. There is so much we need to do to shorten the time to diagnosis, ensure access to care, help families navigate countless issues, and reach more people who need support and answers. We’ll get there together.

**Life is beautiful not because of the things we see or the things we do. Life is beautiful because of the people we meet.** The entire year of 2022 was a bit of a whirlwind. I met with funders and clinicians and community members and partners, and international organizations. And each time, I walked away astounded by your perseverance, your dedication, and your support of IDF—and your support of each other.

It turns out that Mr. Sinek is right: together is better. Thank you for allowing me to join all of you on this journey together.

# Meet our leadership

The Immune Deficiency Foundation leadership team is composed of a talented group of individuals who are dedicated to moving IDF forward to better help the individuals diagnosed with PI. We asked our leaders to answer this question in ten words or less — **What makes our organization different from others?** Check out their answers below.



**Lynn Albizo**

*Vice President, Public Policy*

*"We empower community advocates and make change for the better!"*



**Brian Lloyd**

*Chief Technology Officer*

*"People focused, innovative, results oriented."*



**Katherine Antilla**

*Vice President, Education*

*"A trusted leader providing support and information in the PI community."*



**Sarah Rose**

*Vice President, Business Operations (CFO)*

*"The dedication of our staff."*



**Tammy C. Black**

*Chief Communications Officer*

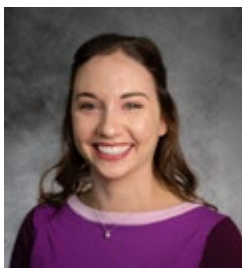
*"We strive to do better. Every day."*



**Christopher Scalchunes**

*Vice President, Research*

*"We provide hope and answers."*



**Alissa Creamer**

*Senior Director, Community Services*

*"Our community cares. You're never alone on your PI journey."*



**Aimee Yrlas Simpson**

*Vice President, Institutional Advancement and Strategic Partnerships*

*"We invest to make life-changing impact!"*



**Christopher Duckett**

*Director, Talent Management*

*"The engagement of our community."*

# Our accomplishments

## EDUCATION



We experienced a year of record growth educating individuals and families about primary immunodeficiency. The IDF team created new resources, hosted more than 135 educational sessions online, and contacted more medical professionals than ever before.

### +33%

increase in event attendees over 2021.



### 103,209

Distributed educational materials to patients and families at no cost to them.

“IDF has done a **FANTASTIC** job once again, and provided top-quality, important programming available to attendees worldwide. Three cheers for the whole IDF Team who have made this virtual experience so compelling & worthwhile!”

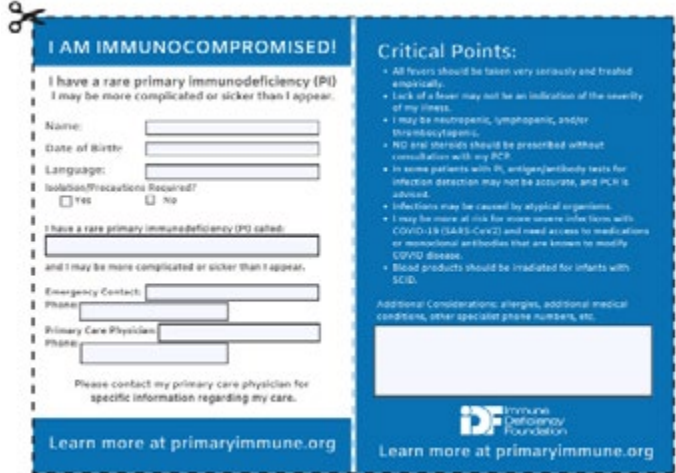


## Increasing knowledge in the medical community.

### +289%

 increase in discussions and connections with medical professionals compared to 2021.

More healthcare providers are now better-equipped to diagnose and treat PI patients, which is a significant step towards improving overall health outcomes.



Developed and approved by the IDF Nurse Advisory Committee, the “I Am Immunocompromised Card” was born. Individuals can order or download the card, fill it out, and keep it in their wallet so that emergency care providers can easily find the information they need on that individual’s primary immunodeficiency.

# PUBLIC POLICY

We pride ourselves in helping shape policies that reflect the values and priorities of the primary immunodeficiency community. This year was no different. We connected a whole nation of individuals to better represent the rare disease community, helping to improve healthcare access and health equity.

## A huge win for IDF and the PI community.

On December 23, 2022, Congress passed legislation making payment for the services and supplies needed for home infusions of intravenous immunoglobulin (IVIg) a permanent Medicare benefit for those with primary immunodeficiency (PI). The move comes nearly a decade after then-President Obama signed the Medicare IVIG Access Act (HR 1845) into law, creating the initial Medicare IVIG demonstration project.

IDF has been working to address the Medicare home IVIG hole for many years, championing the demonstration project and its two extensions. Advocates from the PI community have been integral in putting faces to the issue and maintaining steady pressure to address it with permanent legislation.

“This is a huge win for IDF and the primary immunodeficiency community. For 10 years, Medicare beneficiaries in need of IVIG have benefited from receiving home infusions through the Medicare IVIG demonstration. Now our community has a permanent benefit without needing to enroll in a time-limited demonstration,” said Lynn Albizo, IDF’s vice president of public policy.



# +51%

increase in community letters sent to state and federal legislators supporting IDF’s policy priorities.



- Added four more **Rare Diseases Advisory Councils** (CO, GA, ME, CT).
- Two more states enacted 2022 legislation **prohibiting copay accumulators** (ME, WA).
- Two states passed legislation **removing barriers to plasma donation centers** (CA, NY).

# CONNECTION AND SUPPORT

Having connections and support when navigating a life with primary immunodeficiency is vital for overall well-being and success. We are proud to have more than **530 volunteers** supporting IDF's mission with 125 of those individuals volunteering specifically to provide peer support!

***“What I appreciated the most and what I got the most out of IDF’s Peer Support program was the camaraderie, knowing that there was someone who understood and who was going through it in a real way. They understood about infusions and what happens when you try to find childcare and the other challenges we had,”***

***- Amy Ferreira, Parent of child with XLA***

**1,453**

individuals made requests and/or asked for advice addressing more than 1,850 topics that were answered in 72 hours or less through Ask IDF.

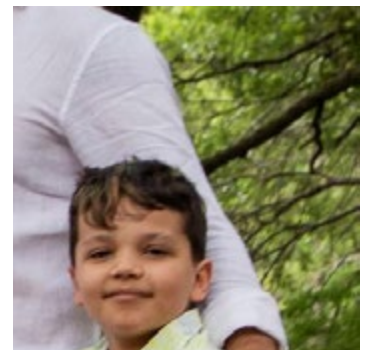
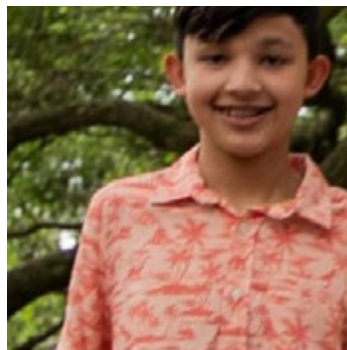


**+23%**

increase in social media followers compared to 2021.

**1,400**

individuals received support through **236** Get Connected Group meetings.



**881,747**

individuals accessed **primaryimmune.org** for information and support.

**2,640**

connections were made at the in-person walks that raised awareness and more than \$853,400, so IDF can continue its research, education, and advocacy efforts.

*\*Amy Ferreira, second from left, is an IDF Peer Support volunteer. Amy is shown with, from left, son Jimmy, husband David, and son Eli, diagnosed with X-linked agammaglobulinemia (XLA).*





# RESEARCH

Read about the research grants awarded by IDF, allowing researchers to dedicate their time and resources to investigate important questions — playing a critical role in shaping the future of individuals living with primary immunodeficiency.

## 2022 White Paper Challenge awardees

In 2021, IDF issued a White Paper Challenge to help address: innovative practices to expand PI awareness in communities of color, methods to increase equity in clinical trials, and novel approaches to shortening the time between diagnosis and treatment. In 2022, three awardees were chosen to receive \$10,000 to support their efforts.



**Dr. David Sanchez** is an allergy and clinical immunology fellow at Mount Sinai School of Medicine. He plans to determine if there is a systemic disparity in PI diagnosis “by examining the age at which ICD codes [International Classification of Diseases codes, often used in insurance billing] associated with PI across New York State appear for patients of color when compared to their white counterparts.” If this analysis shows that people of color are diagnosed later in life, Sanchez plans to reach out to primary care providers (PCPs) in communities of color in New York with targeted education and resources on PI. He will also set up a hotline where PCPs can consult with Mount Sinai clinical immunology fellows on specific cases.



**Dr. Amanda Salih**, a pediatric fellow at Texas Children’s Hospital and instructor at Baylor College of Medicine, is investigating disparities in diagnosing early onset inflammatory bowel disease (VEO-IBD), defined as IBD in a child less than six years old. Salih’s preliminary analysis of patient records established that the average time between the beginning of symptoms and a VEO-IBD diagnosis for children of color is more than twice that of white children. To combat diagnostic disparity, Salih hopes to produce a clinical care tool with recommended diagnostic work-up and treatment approaches that is more objective and reduces diagnostic delays for children of color.



**Dr. Vivian Hernandez-Trujillo** is the founder of the Allergy and Immunology Care Center of South Florida and has helped IDF produce Spanish-language videos on COVID-19. To increase awareness of primary immunodeficiency in Latino/a/x communities, she plans to identify community needs, then develop Spanish-language resources to meet those needs and distribute them at festivals and community events in South Florida.

## 2022 Research Grants

**\$140,763** in research grants was awarded to four grantees.

**Dr. Joud Hajjar**, an assistant professor at the Baylor College of Medicine, focuses her awarded research funds on gut microbiome and inflammation in those living with common variable immune deficiency (CVID).

**Dr. Brenna LaBere**, a clinical allergy/immunology fellow at Boston Children’s Hospital, hopes to develop a way to better measure immune dysregulation through measurement of T cell populations and quality of life metrics.

**Dr. Beth Thielen**, assistant professor at the University of Minnesota, will help establish genetic diagnoses in people with PI who haven’t gotten an answer from standard genetic testing.

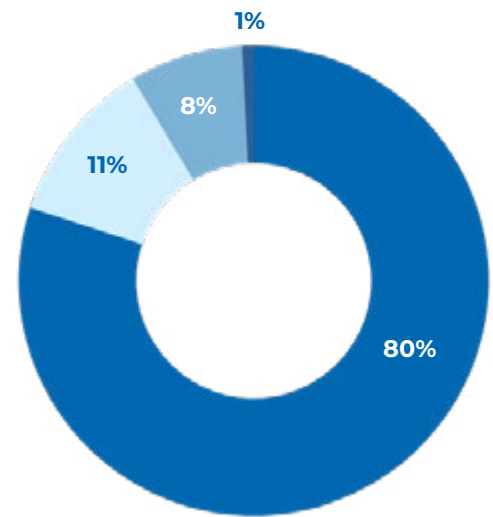
**Dr. Artemio Jongco III**, who is an associate professor at the Feinstein Institutes of Medical Research, plans to look at maternal characteristics for newborns with temporary T cell lymphopenia.

# 2022 Financials

## REVENUE

FOR THE YEAR ENDING DECEMBER 31, 2022.

Contributions and grants	\$6,980,487
Government grants and other contract revenue	\$993,357
Special events	\$680,121
Other income	\$68,746
<b>Total</b>	<b>\$8,722,891</b>

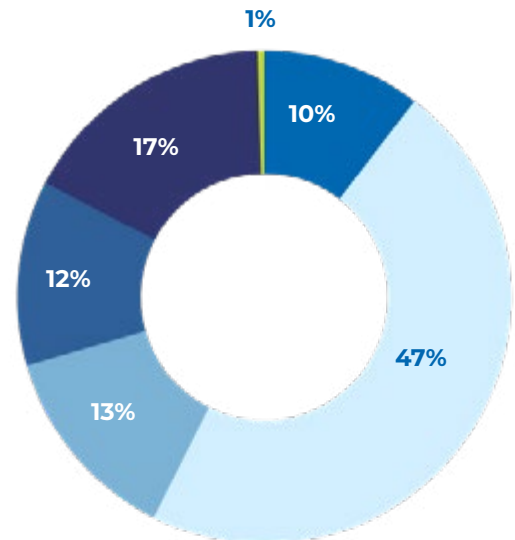


- Contributions and grants
- Government grants and other contract revenues
- Special events
- Other income

## FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2022.

Services to patients and families	\$4,475,038
Administration and finance	\$1,250,232
Marketing and fundraising	\$1,156,100
Medical and scientific	\$990,379
Net investment loss	\$1,610,899
Loss on asset disposal	\$40,684
<b>Total</b>	<b>\$9,523,332</b>



- Services to patients and families
- Administration and finance
- Marketing and fundraising
- Medical and scientific
- Net investment loss
- Loss on asset disposal

# STATEMENT OF FUNCTIONAL EXPENSES

FOR THE YEAR ENDING DECEMBER 31, 2022.

	PROGRAM SERVICES		SUPPORTING SERVICES		Total
	Medical & Scientific	Services to Patients & Families	Admin & Finance	Marketing & Fundraising	
Salaries	\$360,188	\$1,774,511	\$800,815	\$587,958	\$3,523,472
Employee benefits	\$46,318	\$239,220	\$124,246	\$74,526	\$484,310
Payroll taxes, etc.	\$28,149	\$141,600	\$58,214	\$47,985	\$275,948
<b>Total</b>	<b>\$434,655</b>	<b>\$2,155,331</b>	<b>\$983,275</b>	<b>\$710,469</b>	<b>\$4,283,730</b>
Advertising	\$0	\$51,897	\$0	\$819	\$52,716
Awards & grants	\$133,020	\$0	\$0	\$0	\$133,020
Bank fees	\$4,499	\$19,796	\$6,456	\$32,346	\$63,097
Consulting fees	\$217,490	\$1,397,401	\$64,149	\$71,042	\$1,750,082
Dues & subscriptions	\$17,867	\$126,657	\$26,039	\$13,374	\$183,937
Excise tax	\$0	\$9,482	\$0	\$0	\$9,482
Insurance	\$10,513	\$16,942	\$6,227	\$4,538	\$38,220
Interest	\$0	\$0	\$1,604	\$0	\$1,604
Occupancy	\$35,140	\$137,201	\$59,999	\$31,679	\$264,019
Permits & licenses	\$122	\$0	\$764	\$6,470	\$7,356
Postage & shipping	\$4,321	\$39,546	\$3,352	\$50,320	\$97,539
Professional fees	\$3,022	\$11,800	\$4,338	\$2,725	\$21,885
Rental & maintenance of equipment	\$6,328	\$21,723	\$6,990	\$4,391	\$39,432
Repairs & maintenance	\$1,509	\$5,893	\$2,165	\$1,361	\$10,928
Staff development	\$169	\$7,590	\$3,538	\$1,538	\$12,835
Supplies	\$18,703	\$90,480	\$13,468	\$53,487	\$176,138
Telephone	\$14,934	\$49,336	\$15,257	\$8,737	\$88,264
Training, conference, conventions & meetings	\$53,707	\$194,675	\$17,447	\$120,218	\$386,047
Transportation/travel	\$13,302	\$56,992	\$4,913	\$23,584	\$98,791
<b>Total</b>	<b>\$969,301</b>	<b>\$4,392,742</b>	<b>\$1,219,981</b>	<b>\$1,137,098</b>	<b>\$7,719,122</b>
Depreciation amortization	\$21,078	\$82,296	\$30,251	\$19,002	\$152,627
<b>Grand totals</b>	<b>\$990,379</b>	<b>\$4,475,038</b>	<b>\$1,250,232</b>	<b>\$1,156,100</b>	<b>\$7,871,749</b>

# STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

FOR THE YEAR ENDING DECEMBER 31, 2022.

	without donor restrictions	with donor restrictions	Total
<b>PUBLIC SUPPORT AND REVENUE</b>			
Public support & revenue			
Contributions & grants	\$5,784,360	\$1,196,127	\$6,980,487
Government grants & other contract revenue	\$993,537	\$0	\$993,537
Other income	\$68,746	\$0	\$68,746
Special events	\$680,121	\$0	\$680,121
Net assets released from restrictions	\$369,053	(\$369,053)	\$0
<b>Total public support and revenue</b>	<b>\$7,895,817</b>	<b>\$827,074</b>	<b>\$8,722,891</b>
<b>EXPENSES AND LOSSES</b>			
Program services			
Medical & scientific	\$990,379	\$0	\$990,379
Services to patients & families	\$4,475,038	\$0	\$4,475,038
<b>Total program services</b>	<b>\$5,465,417</b>	<b>\$0</b>	<b>\$5,465,417</b>
Supporting services			
Administration & finance	\$1,250,232	\$0	\$1,250,232
Marketing & fundraising	\$1,156,100	\$0	\$1,156,100
<b>Total supporting services</b>	<b>\$2,406,332</b>	<b>\$0</b>	<b>\$2,406,332</b>
Losses			
Net investment loss	\$1,610,899	\$0	\$1,610,899
Loss on asset disposal	\$40,684	\$0	\$40,684
<b>Total losses</b>	<b>\$1,651,583</b>	<b>\$0</b>	<b>\$1,651,583</b>
<b>Total expenses and losses</b>	<b>\$9,523,332</b>	<b>\$0</b>	<b>\$9,523,332</b>
Change in net assets	(\$1,627,515)	\$827,074	(\$800,441)
Net assets, beginning of the year	\$13,349,405	\$493,046	\$13,842,451
Net assets, end of year	\$11,721,890	\$1,320,120	\$13,042,010

# Meet our volunteer leadership

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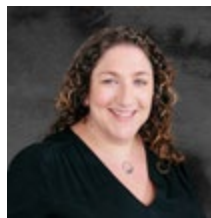
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*Secretary*



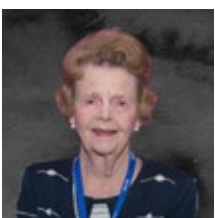
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IDF supporters ensure IDF can continue to provide educational materials and local programming to patients and families, as well as healthcare professionals. IDF greatly appreciates these steadfast supporters and all of our individual contributors for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

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### National presenting walk sponsor

**Takeda**

### National walk sponsors

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Pharming (12 walks)  
Kedron Biopharma (2 walks)  
Enzyvant  
Bio Products Laboratory  
Accredo  
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