CELEBRATING 40 YEARS
OF ADVOCACY, EDUCATION, AND SUPPORT FOR THOSE LIVING WITH PRIMARY IMMUNODEFICIENCY.
The Immune Deficiency Foundation improves the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency through fostering a community empowered by advocacy, education, and research.
A FEW WORDS:
2020 A YEAR FOR REFLECTING AND PROGRESSING

What began as a year to celebrate the Immune Deficiency Foundation’s 40th anniversary, quickly pivoted to a year that would challenge IDF’s ability to respond to unprecedented events.

As the global pandemic hit, our employees were sent to work safely from home, not knowing when they would return. Not knowing what one day would look like compared to the next is actually a very familiar feeling for members of the PI community. What did become known was that the uncertainty created significant opportunities for IDF to respond to the needs of the PI community. And COVID-19 quickly became the issue of greatest concern.

Our response to COVID-19 focused on fulfilling our constituent promise of providing transparency, trust, and compassion. IDF immediately developed a COVID-19 portal, which became a critical resource that was accessed more than 159,037 times over the course of the following six months, providing individuals living with PI critical information about COVID-19. IDF also transitioned all planned in-person events to a virtual environment and developed multiple programs addressing the need for plasma and at-home treatment, and reached out virtually to community members and healthcare professionals in real-time across the globe.

This response to the pandemic was an enormous team effort. I, and the entire board, are so appreciative to the IDF staff who worked tirelessly to provide support and services to the PI community without interruption during a disruptive time. We are also grateful for the warm and enthusiastic response from the PI community for participating, embracing, and including so many of their own family members, friends, and newly identified PI patients at IDF virtual events. Finally, we’d like to thank IDF corporate partners and personal donors who supported our efforts throughout the year.

As we continue to navigate through a global pandemic, we are first-hand witnesses of the effects and its toll on achieving our mission to improve the diagnosis, treatment, and quality of life of people affected by primary immunodeficiency.

We are confident that with your dedicated support, we will continue to grow and provide the advocacy, education, and research that the PI community needs. Thank you for your commitment and support to improving the lives of those living with PI. Every day, we prove that we are stronger together.

Best regards,
John Seymour, PhD, LMFT

Chair, IDF Board of Trustees
IDF IN ACTION

Check out the highlights of how IDF continued to improve the diagnosis, treatment, and quality of life of people affected by PI through fostering a community empowered by advocacy, education, and research during a global pandemic.

IDF Hosted 46 virtual and 2 in-person educational forums covering 37 TOPICS with more than 50 presenters. More than 4,832 attendees.

ENGAGED 1,400 medical professionals (in US & PR) providing, responding, and educating them on PI. Attended 99 virtual medical conferences, consulting with 83 physician experts.

Growing our impact with 1,566 first-time attendees.

Distributed 165,482 education materials at no cost to patients and families.

WORKING TOGETHER

Volunteers are the heart of IDF and in 2020 we were proud to have more than 483 active volunteers.

GET CONNECTED GROUPS

In 2020, there were 34 Get Connected Leaders located across the country coordinating 168 virtual get-togethers attended by 1,715 individuals, connecting those living with PI.

PEER SUPPORT PROGRAM

• Connecting people and patients who share similar relationships to PI.
• 127 individuals volunteered to offer one-to-one peer support.

PLASMA PARTNER PROGRAM

• 222 individuals volunteered their time as plasma awareness coordinators and created awareness campaigns in their area to recruit and raise awareness about plasma donations.
UNITING THE PI COMMUNITY

IDF 2020 NATIONAL SUMMIT
An online gathering, formerly known as IDF Retreats, designed for everyone in the PI community to learn and connect in more than 20 educational sessions.

505 attendees 57% were first-time IDF event attendees

IDF YOUTH EVENTS
IDF dedicated an entire week to its youth, striving to engage and educate youth living with PI. IDF hosted 6 virtual events with over 179 youth attendees.

IDF WALK FOR PI
The very first 100% virtual walk season helped to unite the PI community to help create better lives for individuals living with these rare, and chronic disorders.

32 cities across the U.S.
1,700 walkers
296 teams

57% were first-time IDF event attendees

RARE OF THE RARE
The first virtual summit focused on the rarest PI diagnoses.

21 educational sessions 386 attendees

OPTIMIZING THE ONLINE USER EXPERIENCE
With an IDF My Account, users can now customize their the way they receive updates (mail, email, text) from IDF.

More than 932,938 users accessed
WWW.PRIMARYIMMUNE.ORG

More specifically, the IDF COVID-19 portal was accessed more than 159,037 times by individuals looking for more information about COVID-19 and living with PI.

399 requests were submitted about locating specialists through our online tool the Clinician Finder.

INFORMATION REQUESTS
9,765 individuals made requests for support and information on a variety of topics including COVID-19 and PI.

4,326 CGD website
14,771 SCID Compass website
9,765

9,765

1,700 walkers
1,700 walkers

$810,354
$810,354

14,771
14,771
ADVANCING RESEARCH
Powering critical patient-focused research that will ultimately improve the quality of life for generations to come.

RESEARCH GRANTS
Since 2013, the dollars raised by IDF Walk for PI have been used to establish the IDF Research Grant Program, awarding grants to help improve the diagnosis, treatment, and quality of life of people affected by PI.

7 more research grants were added by the IDF Research Grant Program in 2020.

The 2020 grants were worth $160,000.

Surveys provided insight into the personal impact of PI and COVID-19 to help better educate the community about the pandemic.

2,400 participants participated in 6 COVID-19 focused IDF surveys.

Three abstracts were published, with the ACAAI & AAAAI abstracts being award-winning.

IDF SURVEY RESEARCH

COMMUNICATIONS
Connecting through social media, videos, and beyond!

In response to COVID-19, IDF launched a campaign on social media in honor of #GivingTuesdayNow to promote IDF’s #ChalkingChallenge to share something positive and/or give a gift to IDF to show we are stronger together. We received some incredible photos and raised more than $1,800 in one day thanks to your support!

IDF SOCIAL MEDIA STATS

19,922 IDF likes & 3,761 Walk for PI likes

3,710 IDF followers

19,922 IDF followers

2,104 Followers

7,523 Members

46,681 individuals received the IDF newsletter, IDF Advocate.

39,000 individuals received the monthly e-newsletter, Primary Immune Tribune.

IDF RESOURCE CENTER

Videos housed on the IDF Resource Center were watched more than 225,335 times. IDF uploaded 116 new videos to our YouTube channels. Six new episodes on our podcast, Have you Herd, launched and was played more than 4,100 times.
PUBLIC POLICY

The voice of the PI community.

In 2020, IDF pulled together a steering committee composed of The AIDS Institute, American Autoimmune Related Disease Association (AARDA), IDF, the Lupus Foundation of America, and Susan G Komen to address the concerns and needs of the immunocompromised population as a whole. This committee became known as the Immunocompromised Collaborative.

VIRTUAL ADVOCACY DAY
The annual event is typically held on Capitol Hill, but looked slightly different to follow COVID-19 protocols.

199 patients and family members participated, attending
95 legislative meetings.

STATE ADVOCACY WORKSHOPS
32 patients and family members participated in
30 legislative meetings advocating for access to care, screening & diagnosis, and PI community support for all of those affected by PI.

The COVID-19 pandemic has undoubtedly been challenging for everyone in 2020. However, there have been silver linings for the PI community in the policy realm. For example, IDF has long advocated for expanded access to home infusions and remote care to address various issues, including avoiding exposure to pathogens that could be present in facility settings. Our multi-year advocacy to initiate and extend the Medicare IVIG Demonstration has allowed PI patients on Medicare to receive full coverage of home infusions without any disruption of service and without having to take the risk of exposure to COVID-19 throughout the pandemic. The administration recognized the benefits of home infusion during the pandemic and implemented a temporary expansion of home infusion coverage for many other disease states. The policy arguments that IDF put to the forefront for years finally gained broad acceptance. We no longer have to explain to legislators why it is often safer for individuals to receive treatment at home.

In addition, greater access to telehealth services was implemented nationwide as physicians and patients became more comfortable with remote care, and both public and private insurance provided coverage. As we look ahead to 2021, IDF will continue its advocacy for expanded coverage for telehealth, not just during the pandemic but in the future.
2020 FINANCIALS

REVENUE

<table>
<thead>
<tr>
<th>Revenue Source</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Industry* Contributions and Grants (includes walk funding)</td>
<td>$4,497,871</td>
<td>60.99%</td>
</tr>
<tr>
<td>Contributions - Individuals</td>
<td>$414,719</td>
<td>5.62%</td>
</tr>
<tr>
<td>Government Grants</td>
<td>$1,255,835</td>
<td>17.03%</td>
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<tr>
<td>Contract Revenue</td>
<td>$2,250</td>
<td>0.03%</td>
</tr>
<tr>
<td>Investment Income</td>
<td>$882,451</td>
<td>11.97%</td>
</tr>
<tr>
<td>Special Events - Walks - Individuals (industry reflected above)</td>
<td>$226,378</td>
<td>3.07%</td>
</tr>
<tr>
<td>Special Events - Other</td>
<td>$86,999</td>
<td>1.18%</td>
</tr>
<tr>
<td>Other Miscellaneous</td>
<td>$8,586</td>
<td>0.12%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$7,375,089</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

STATEMENT OF FUNCTIONAL EXPENSES

<table>
<thead>
<tr>
<th>Expense</th>
<th>Amount</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical and Scientific</td>
<td>$754,445</td>
<td>11.55%</td>
</tr>
<tr>
<td>Services to Patients and Families</td>
<td>$4,259,764</td>
<td>65.21%</td>
</tr>
<tr>
<td>Business Operations</td>
<td>$706,192</td>
<td>10.81%</td>
</tr>
<tr>
<td>Marketing and Fundraising</td>
<td>$812,140</td>
<td>12.43%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$6,532,541</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

*This consists of contributions for our programs, patient education and events from pharmaceutical, biotechnology and medical device companies.
<table>
<thead>
<tr>
<th></th>
<th>PROGRAM SERVICES</th>
<th>SUPPORTING SERVICES</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Medical &amp; Scientific</td>
<td>Services to Patients &amp; Families</td>
<td></td>
</tr>
<tr>
<td>Salaries</td>
<td>$316,409</td>
<td>$1,811,194</td>
<td>$2,877,858</td>
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<tr>
<td>Employee Benefits</td>
<td>$26,856</td>
<td>$285,007</td>
<td>$302,163</td>
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<tr>
<td>Payroll Taxes, etc.</td>
<td>$24,857</td>
<td>$141,848</td>
<td>$21,938</td>
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<tr>
<td>Total</td>
<td>$368,122</td>
<td>$2,238,049</td>
<td>$3,555,401</td>
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<tr>
<td>Advertising</td>
<td>$0</td>
<td>$12,018</td>
<td>$0</td>
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<tr>
<td>Awards &amp; Grants</td>
<td>$196,197</td>
<td>$10,000</td>
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<td>Bank Fees</td>
<td>$5,374</td>
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<tr>
<td>Dues &amp; Subscriptions</td>
<td>$5,416</td>
<td>$23,871</td>
<td>$9,546</td>
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<td>Insurance</td>
<td>$2,949</td>
<td>$22,832</td>
<td>$5,483</td>
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<td>Interest</td>
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<td>$0</td>
<td>$6,980</td>
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<td>Occupancy</td>
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<tr>
<td>Permits &amp; License</td>
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<td>$157</td>
<td>$0</td>
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<td>Postage and Shipping</td>
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<td>$86,111</td>
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<td>Professional fees</td>
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<td>$1,289,494</td>
<td>$190,195</td>
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<tr>
<td>Rental &amp; Maintenance of Equipment</td>
<td>$3620</td>
<td>$23,301</td>
<td>$6,017</td>
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<tr>
<td>Repairs &amp; Maintenance</td>
<td>$103</td>
<td>$607</td>
<td>$191</td>
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<tr>
<td>Staff Development</td>
<td>$0</td>
<td>$23,869</td>
<td>$13,710</td>
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<tr>
<td>Supplies</td>
<td>$3,162</td>
<td>$87,766</td>
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<tr>
<td>Telephone</td>
<td>$4,197</td>
<td>$58,306</td>
<td>$5,702</td>
</tr>
<tr>
<td>Training, Conference, Conventions, &amp; Meetings</td>
<td>$3,743</td>
<td>$125,059</td>
<td>$882</td>
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<tr>
<td>Travel</td>
<td>$4,468</td>
<td>$21,706</td>
<td>$1,857</td>
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<tr>
<td>Total</td>
<td>$748,638</td>
<td>$4,225,433</td>
<td>$695,393</td>
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<tr>
<td>Depreciation Amortization</td>
<td>$5,807</td>
<td>$34,331</td>
<td>$10,799</td>
</tr>
<tr>
<td>Grand Totals</td>
<td>$754,445</td>
<td>$4,259,764</td>
<td>$706,192</td>
</tr>
</tbody>
</table>
# Statement of Activities and Changes in Net Assets

For the Year Ending December 31, 2020.

## Public Support and Revenue

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Public Support</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions and Grants</td>
<td>$4,246,672</td>
<td>$668,168</td>
<td>$4,914,840</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>$559,124</td>
<td>($559,124)</td>
<td>$0</td>
</tr>
<tr>
<td><strong>Total public support</strong></td>
<td>$4,805,796</td>
<td>$109,044</td>
<td>$4,914,840</td>
</tr>
<tr>
<td>Government Grants and Other Contract Revenue</td>
<td>$1,255,835</td>
<td>$0</td>
<td>$1,255,835</td>
</tr>
<tr>
<td><strong>Revenue</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investment Income, Net</td>
<td>$882,451</td>
<td>$0</td>
<td>$882,451</td>
</tr>
<tr>
<td>Other Income</td>
<td>$8,586</td>
<td>$0</td>
<td>$8,586</td>
</tr>
<tr>
<td>Special Events</td>
<td>$313,377</td>
<td>$0</td>
<td>$313,377</td>
</tr>
<tr>
<td><strong>Total Revenue</strong></td>
<td>$1,204,414</td>
<td>$0</td>
<td>$1,204,414</td>
</tr>
<tr>
<td><strong>Total Public Support and Revenue</strong></td>
<td>$7,266,045</td>
<td>$109,044</td>
<td>$7,375,089</td>
</tr>
<tr>
<td><strong>Expenses</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Program Services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical and Scientific</td>
<td>$754,445</td>
<td>$0</td>
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<tr>
<td>Services to Patients and Families</td>
<td>$4,259,764</td>
<td>$0</td>
<td>$4,259,764</td>
</tr>
<tr>
<td><strong>Total Program Services</strong></td>
<td>$5,014,209</td>
<td>$0</td>
<td>$5,014,209</td>
</tr>
<tr>
<td>Supporting Services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administration and Finance</td>
<td>$706,192</td>
<td>$0</td>
<td>$706,192</td>
</tr>
<tr>
<td>Marketing and Fundraising</td>
<td>$812,140</td>
<td>$0</td>
<td>$812,140</td>
</tr>
<tr>
<td><strong>Total Supporting Services</strong></td>
<td>$1,518,332</td>
<td>$0</td>
<td>$1,518,332</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td>$6,532,541</td>
<td>$0</td>
<td>$6,532,541</td>
</tr>
<tr>
<td>Change in Net Assets</td>
<td>$733,504</td>
<td>$109,044</td>
<td>$842,548</td>
</tr>
<tr>
<td>Net Assets, Beginning of the Year</td>
<td>$10,062,179</td>
<td>$541,271</td>
<td>$10,603,450</td>
</tr>
<tr>
<td>Net Assets, End of Year</td>
<td>$10,795,683</td>
<td>$650,315</td>
<td>$11,445,998</td>
</tr>
</tbody>
</table>
## PLASMA SAVES LIVES

### Raising Awareness & Giving Plasma the Recognition It Deserves

Over the last couple of years, there has been more talk about plasma donation and its importance. There is not denying that plasma plays a crucial role to our health; it is one of the most critical components in blood, which is 55% plasma. Plasma itself has a wide range of uses, including creating plasma-derived therapies that benefit more than 70% of the primary immunodeficiency (PI) community. **Plasma saves lives.**

Plasma is collected through whole blood donation, meaning that blood is withdrawn from a donor and the plasma is filtered out before the remaining blood is returned back into the donor. This donated plasma is then used to create products that help with clotting blood, fighting diseases and boosting the immune system, and other critical functions. The process takes about an hour and can be done twice within a seven-day period.

However, only a small number of people who are eligible to donate plasma in the U.S. donate. And in many cases, a donor must donate plasma more than once for their donation to be a viable resource for plasma-derived therapies. Simply put, we need more donors. We need more awareness surrounding the lifesaving yellow liquid. We need heroes to step up and help those who rely on plasma-derived therapies to live.

The Immune Deficiency Foundation (IDF) launched the **Plasma Hero** initiative to recognize and thank those who donate plasma or raise awareness. In doing so, we hope to help more individuals learn about plasma, how it’s used, and who it helps while encouraging people to donate plasma (and return more than once so that plasma can be utilized to save lives). It’s time to step up and be a hero. **Donate plasma.**

### CELEBRATING 40 YEARS OF IDF!

IDF celebrated its 40th birthday on December 11, 2020. Not only did we raise over **$170,000** from the generous birthday donations our community made to help improve the lives of those living with PI, but we also received some amazing birthday messages reminding us why we do what we do. Check out some of the birthday messages below!

“Wishing IDF the happiest of Birthdays! What started at a kitchen table has grown to accomplish incredible things for the PI community. The successes of your efforts are honorable, life-saving & most certainly worth celebrating. Congratulations on an impactful 40 years!” - Lauren S.

Happy Birthday! I appreciate you all! Your help, resources, kindness, & inspiration have added quality to my life. Your advocacy has saved my life. I appreciate you every day. Every infusion. Every medical appointment. Thank you! - Marilyn McVicker

“Happy Birthday to IDF! This foundation has made such a wonderful difference to the people with PI. People like me! Thank you for all you do to keep us educated and informed of what is truly safeguarding my life & my precious two grandsons with our PI. - Brenda

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<table>
<thead>
<tr>
<th>PUBLIC SUPPORT AND REVENUE</th>
<th>WITHOUT DONOR RESTRICTIONS</th>
<th>WITH DONOR RESTRICTIONS</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Contributions and Grants</strong></td>
<td>$4,246,672</td>
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<td><strong>$4,914,840</strong></td>
</tr>
</tbody>
</table>

| **Government Grants and Other Contract Revenue** | **$1,255,835** | $0 | **$1,255,835** |

<table>
<thead>
<tr>
<th><strong>INCOME</strong></th>
<th><strong>$1,204,414</strong></th>
<th>$0</th>
<th><strong>$1,204,414</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Investment Income, Net</strong></td>
<td><strong>$882,451</strong></td>
<td>$0</td>
<td><strong>$882,451</strong></td>
</tr>
<tr>
<td><strong>Other Income</strong></td>
<td><strong>$8,586</strong></td>
<td>$0</td>
<td><strong>$8,586</strong></td>
</tr>
<tr>
<td><strong>Special Events</strong></td>
<td><strong>$313,377</strong></td>
<td>$0</td>
<td><strong>$313,377</strong></td>
</tr>
</tbody>
</table>

| **TOTAL REVENUE** | **$7,266,045** | $109,044 | **$7,375,089** |

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<table>
<thead>
<tr>
<th><strong>EXPENSES</strong></th>
<th><strong>$6,532,541</strong></th>
<th>$0</th>
<th><strong>$6,532,541</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program Services</strong></td>
<td><strong>$5,014,209</strong></td>
<td>$0</td>
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<td><strong>$812,140</strong></td>
<td>$0</td>
<td><strong>$812,140</strong></td>
</tr>
</tbody>
</table>

| **TOTAL EXPENSES** | **$6,532,541** | $0 | **$6,532,541** |

| **Change in Net Assets** | **$733,504** | $109,044 | **$842,548** |

| **Net Assets, Beginning of the Year** | **$10,062,179** | $541,271 | **$10,603,450** |
| **Net Assets, End of Year** | **$10,795,683** | $650,315 | **$11,445,998** |
LEADERSHIP

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Vice Chair
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Development Chair
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Terry Halper
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Amy Walsh

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Vice President of Communications
Marcy Chang
Vice President of Institutional Advancement
Brian Fitzek
Associate Vice President of Community Services
Hector J. Garcia, Jr.
Executive Vice President of Programs and Services
Sarah Rose
Chief Financial Officer
Christopher Scalphunes
Vice President of Research

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