HEALTH RESEARCH ALLIANCE
COVID-19 MEMBER SURVEY RESULTS

MCDERMOTT & WHITE
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<thead>
<tr>
<th>ACRONYM</th>
<th>EXPLANATION</th>
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<tbody>
<tr>
<td>CY</td>
<td>Calendar Year</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus Group Discussion</td>
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<td>FY</td>
<td>Fiscal Year</td>
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<td>HRA</td>
<td>Health Research Alliance</td>
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<tr>
<td>NCE</td>
<td>No Cost Extension</td>
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<td>PPP</td>
<td>Paycheck Protection Program</td>
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<tr>
<td>RFA</td>
<td>Request for Application</td>
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<td>SC</td>
<td>Steering Committee</td>
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<tr>
<td>WFH</td>
<td>Work From Home</td>
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<tr>
<td>YOY</td>
<td>Year-over-Year</td>
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EXECUTIVE SUMMARY

The Health Research Alliance (HRA) is a collaborative member organization of nonprofit research funders that is committed to maximizing the impact of biomedical research to improve human health. The 90+ member organizations include voluntary health agencies, private foundations, and operating foundations that are funders of health research. All member organizations share a common interest in speeding the translation of biomedical science discoveries into applications that improve health, and in identifying and adopting best practices in funding health research\(^1\).

HRA engaged external consultants to survey its members to better understand impacts of the COVID-19 pandemic on the organizations that fund medical research. This report is intended to present the survey results, and to communicate the impacts of the COVID-19 pandemic on member organizations. Specific organizational impacts of interest explored included:

- Revenues (e.g., fundraising/endowment performance, revenue diversification).
- Operations (e.g., staff changes, restructuring, impact of remote work other bottom-line adaptations).
- Research grant awards (e.g., number of awards, extensions, diversity of awards); and
- Programming (e.g., conversion to virtual, cancelling, introducing new programming).

The survey was developed based on the following key objectives:
- Document top-line, bottom-line, and net impacts on funding streams.
- Document operational adaptations.

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\(^1\) Source: https://www.healthra.org/

KEY FINDINGS

<table>
<thead>
<tr>
<th>#1</th>
<th>The overall biggest impact of COVID-19 on HRA members surveyed was the shift to remote and/or telework.</th>
</tr>
</thead>
<tbody>
<tr>
<td>#2</td>
<td>The overall second biggest impact of COVID-19 on HRA members surveyed was on research/grant awards and associated activities.</td>
</tr>
<tr>
<td>#3</td>
<td>The overall third biggest impact of COVID-19 on HRA members surveyed was on fundraising revenues.</td>
</tr>
</tbody>
</table>

60% Percentage of survey respondents who report that COVID-19 impacted the way their organization awards and administers research awards and/or grants.

50% Percentage of fundraising members who report that the total amount of funds raised by their organization in calendar year 2020 decreased compared to calendar year 2019.
• Document impacts to date on fundraising, research grant awards, and programming.
• Document key pain points among member organizations.
• Illustrate key impacts using qualitative data.

**KEY FINDINGS**

**Overall, the Switch to Remote / Telework had the Biggest Reported Impact Across all Organization Types**
Across organization types, the switch to remote work and/or telework had the biggest reported impact on HRA members. However, most members reported that remote work did not adversely impact organizational or individual performance. The largest organizational impact from the shift to work from home (WFH) has been on organizational culture.

**Impacts Varied by Organization Type**
Organizations that rely on fundraising reported more significant negative impacts than organizations that operate through an endowment. For this reason, results are most often disaggregated by organization type. Declining revenues from fundraising was the top reported impact among fundraising members with 50% of fundraising organizations reporting that the total amount of funds raised in calendar year (CY) 2020 decreased compared to CY 2019. The average reported decline in total revenues was 35% year-over-year (YOY). Conversely, 59% of endowment-based organizations reported that their organization’s endowment grew in 2020.

**Research/Grant Awards Spend and Procedures were Impacted**
The impact on annua spend on research/grant award and associated activities differs by organization type, with fundraising organization reported the most significant decline in YoY spend. However, all organization types indicated that organizational flexibility was required (shifting deadlines, moving to virtual methods, no-cost extensions, etc.) to meet the needs of researchers.

**Impacts Were Both Positive and Negative**
The most consistently reported negative impact was the decrease in funds raised by fundraising organizations. Corresponding decreases in research grants awarded were also reported. Additional negative impacts reported included isolation and negative impacts on employees. However, unexpected positive impacts including new partnerships, as well as positive shifts in organizational culture because of the shift to WFH were also reported. Respondents struggled to assign an overall characterization of the pandemic as either overwhelmingly positive or negative.
SURVEY METHODOLOGY

The final evaluation examined the following dimensions of the COVID-19 pandemic on HRA members:

- Revenues (e.g., fundraising/endowment performance, revenue diversification);
- Operations (e.g., staff changes, restructuring, impact of remote work other bottom-line adaptations);
- Research grant awards (e.g. number of awards, extensions, diversity of awards); and
- Programming (e.g., conversion to virtual, cancelling, introducing new programming).

The research team conducted a series of key informant interviews (KIIs) with a Steering Committee (SC) of HRA senior leadership and HRA members. The researchers also conducted three remote (Zoom) Focus Group Discussions (FGDs) with HRA members to further understand the impacts of COVID-19 on members, and the differences in impacts based on organization type (Fundraising, Endowment, Society/Other)

FGD 1: January 20, 2021; Fundraising Members [six participants]
FGD 2: January 21, 2021; Endowment Members [five participants]
FGD 3: January 21, 2021; Society/Other Members [three participants]

Pilot Survey: The research team piloted the online survey (Survey Monkey) in February and March 2021 and received eight (8) responses including feedback on the survey itself. These pilot results were analysed by the research team and reviewed with the Steering Committee. These results and feedback informed changes to the final survey instrument.

Census Member Survey: A survey (SurveyMonkey) was administered to HRA’s entire membership (excluding organizations who participated in the pilot survey) in March 2021. Results were collected through April 2021. Inclusive of the pilot responses, 62 organizations partially or completely filled out the survey.

<table>
<thead>
<tr>
<th>Primary Data Collection</th>
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</thead>
<tbody>
<tr>
<td>Steering Committee KII</td>
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<tr>
<td></td>
</tr>
<tr>
<td>FGDs</td>
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<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
</tr>
<tr>
<td>Survey Responses</td>
</tr>
<tr>
<td>(Fully or Partially</td>
</tr>
<tr>
<td>Complete)</td>
</tr>
<tr>
<td></td>
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<td></td>
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</tbody>
</table>

ANALYSIS AND VALIDATION

Quantitative Analysis: Quantitative survey data were analysed in Microsoft Excel. Given the nature of the data, the results are primarily in the form of simple descriptive statistics.
Grounded Theory Method: Information obtained from Steering Committee discussions, FGDs, and qualitative survey data were analysed using the Grounded Theory Method. The team derived theories about the impacts of COVID-19 based on the data collected. This was done to avoid preconceived theories about the impacts of COVID-19 and to focus on the data only. Key findings were shared with HRA membership during a webinar on July 22, 2021.

LIMITATIONS

Response Rate: Analysis is limited to the 62 partial and complete responses received. Not all members completed the survey as it was voluntary and not compulsory. In addition, all questions within the survey were voluntary.

Social Desirability Bias: Much of the data was collected from organizational leaders. Therefore, we consider that there was a potential social desirability bias. This can lead participants to report more positive outcomes to demonstrate their capabilities as leaders.

Timing of the Fiscal Year: 22 respondents reported that their fiscal year is different than the calendar year. It is likely that the full impacts of COVID-19 on some organizations had not been felt or captured at the time of this survey. Due to the nature of COVID-19 occurring during the same calendar timeframe for all organizations, the researchers, in collaboration with the Steering Committee, determined that it was best for the sake of consistency to collect all data based on calendar year.
KEY FINDINGS

OVERALL IMPACTS

From the FGDs and KIIs, the following organizational impacts of COVID-19 on HRA members were hypothesized and tested:

- Impact on fundraising revenues
- Endowment performance
- Organizational reorganization and/or restructuring (including layoffs and furloughs)
- Remote / telework
- Research/grant awards and associated activities (review meetings, disbursement, extension, use, etc.)
- Non-research programming
- Uncertainty impacting our ability to plan for the future

Survey respondents were asked to rank the top impacts of COVID-19 from the list above (with an option to indicate an “other” impact). Overall, the biggest self-reported impact across organization types was the switch to remote and/or telework. The second biggest reported impact across organization types was the impact on research/grant awards and associated activities. However, Fundraising organizations reported significant negative impacts to their fundraising revenues. In contrast, endowment-based organizations reported improved endowment performance in 2020.

The sections that follow will address these top three impacts in more detail. The full set of survey results addressing the full set of hypothesized impacts can be found in Appendix 5.

<table>
<thead>
<tr>
<th>Top 3 Biggest Impacts of COVID19 by Organization Type</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fundraising</strong></td>
</tr>
<tr>
<td>#1</td>
</tr>
<tr>
<td>#2</td>
</tr>
<tr>
<td>#3</td>
</tr>
</tbody>
</table>
1. REMOTE & TELEWORK

The switch to remote and telework was the top reported organizational impact of COVID-19 across organization types. Both the number of employees working from home and the average days per week employees worked from home significantly increased year-over-year for all organization types. Some organizations had already started to make this shift, but others were less prepared. In 2019, across organizations, teleworking (located in the same city as the office but working from home) and remote working (working from a different location) was not common for the majority of employees. For those who did have teleworking arrangements in 2019, most teleworking employees worked from home 1-2 days per week. This increased to 4-5 days per week by December 2020.

### December 2020 - On average, how many days per week did teleworking employees commute (work from home)?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>4.65</td>
<td>4.60</td>
</tr>
</tbody>
</table>

### December 2019 - On average, how many days per week did teleworking employees commute (work from home)?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>1.62</td>
<td>1.50</td>
</tr>
</tbody>
</table>

### Teleworking

What percentage of your employees were teleworking at least some of the time?

<table>
<thead>
<tr>
<th></th>
<th>December 2020</th>
<th>December 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>91-100%</td>
<td>29</td>
<td>5</td>
</tr>
<tr>
<td>81-90%</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>71-80%</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>61-70%</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>51-60%</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>41-50%</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>31-40%</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>21-30%</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>11-20%</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>&lt;10%</td>
<td>2</td>
<td>9</td>
</tr>
</tbody>
</table>
Members were asked about specific dimensions of telework and remote work to unpack what aspects of remote and telework were most challenging. Notably, only 38% of respondents agreed or strongly agreed with the statement, “Remote work / telework has presented almost no challenges.” Surprisingly, 72% of respondents agree or strongly agree with the statement, “Remote work / telework has had almost no detrimental impact on organizational performance.” Furthermore, 68% of respondents agree or strongly agree with the statement, “Remote work / telework has had almost no detrimental impact on individual performance.” 60% of respondents agree or strongly agree with the statement, “My organization has a clear remote work / telework strategy.” The biggest impact appears to be on organizational culture, with only 42% of respondents agreeing or strongly agreeing with the statement that “Remote work / telework has not changed our organizational culture.” 38% of respondents disagreed or completely disagreed with that statement.

"100% of staff has been working remotely 100% of the time. We’ve been technologically well-equipped, and staff has been extremely, if not more so, productive. Culture and job satisfaction has suffered, largely due to burnout due to staff decreases.”
- HRA member

To what extent do you agree with the following statements about remote work / telework?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree nor Disagree</th>
<th>Disagree</th>
<th>Completely Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Remote work / telework has not changed our organizational culture.</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>My organization has a clear remote work / telework strategy.</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / telework has presented almost no challenges.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / telework has had almost no detrimental impact on individual performance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / telework has had almost no detrimental impact on organizational performance.</td>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>
Virtual Events
In addition to day-to-day work, members have shifted major events including conferences, scientific review committees, and fundraising activities to virtual formats. While there has been a learning curve and other expected pain points associated with these shifts, this shift has also allowed for greater inclusion and diversity. There have also been cost savings associated with the shift to virtual events. An example of a financially costly event that was canceled during the pandemic included a tradition of flying new grantees out to the organization’s headquarters for an award ceremony. While respondents maintain that face-to-face interactions are invaluable in many respects, they have come to recognize and reflect on the positive impacts of virtual convenings and outreach, and plan to make more permanent shifts to host more hybrid or entirely virtual events. They are interested in how other organizations have managed external virtual engagement and how they plan to continue to integrate virtual engagement in their outreach moving forward. The impacts of migrating to virtual and hybrid fundraising events are addressed more in-depth later in this report.

Differing Experiences and Perceptions of the Impact of Telework
While most organizations agree that organizational productivity (72%) and individual productivity (68%) did not suffer because of the switch to remote and telework, organizations reported different levels of preparedness, and differing expectations for the long-term changes to WFH policies. The focus groups conducted prior to the survey suggest that some of these differences in perception may be driven by one’s position in the organization, with Senior Management having a different view than mid-level and junior employees. Further discussion and exploration are needed to confirm whether there are significant differences by level of seniority.

• “Some of us are working as hard and making it work, others just are using it as an excuse not to be available when they should be.”
• “Major issue has been being able to get technical support when needed. During full closure of office, we were not able to access files remotely so had to download necessary files to flash drives which was cumbersome.”
• “We were not prepared for remote/telework.”
• “Once conditions allow, the foundation will provide a 30-day notice period at the end of which all staff will resume working from the offices.”

• “We've been technologically well-equipped, and staff has been extremely, if not more so, productive. Culture and job satisfaction has suffered, largely due to burnout due to staff decreases.”
• “Complete turnaround. Before COVID, leadership was very much against people working from home. Now they see that it can be done, and staff can be very productive”
• “Organization is office based but had many teleworkers before, the pandemic accelerated that trend.”
• “As a result of the pandemic we have fully embrace a "work from anywhere" approach. Even after the pandemic, we anticipate that most staff will NOT return to the office full time.”
Members were asked to provide advice for their peer organizations. The second most-common topic of advice was around actively managing organizational culture. The long-term impacts of COVID-19 on organizational culture merits further discussion and research.

**Advice on Organizational Culture**
- “Be intentional about org culture.”
- “Check in frequently with your staff members to see how they are doing personally.”
- “Clear, honest communication, even when it must be ambiguous.”
- “Embrace change and communicate transparently & frequently.”
- “Have understanding senior leadership.”
- “Increase communication among team members and within your research community to better understand the challenges and address them as you can.”
- “The people of the organization are the most valuable asset. Taking care of the people that work for the organization has a direct impact on the quality of work and well-being of the organization.”
In 2020, research and grant awards were impacted in terms of the total funds available to spend on awards, increased flexibility within existing awards, and funding directed toward new COVID-19 specific activities. Roughly a quarter of members (24%) reported that they allowed existing awards to be used in new ways in 2020.

Decline in Year-over-Year Spend
On average, all organization types decreased their spend on research awards/grants in calendar year 2020. The magnitude of the decrease varied significantly by organization type. Fundraising organizations report the biggest decline in year-over-year (YOY) spend on both an absolute and percentage basis. Fundraising organizations reported a decrease of $5.4M in annual spend on average (27.3% of 2019 average annual spend). Societies and other organization types reported a decrease of $1.9 million in annual spend on average (13.3% of 2019 average annual spend). Endowment-based organizations reported a decrease of $633k in annual spend on average (1.35% of 2019 average annual spend).
Flexible Award Administration
Most organizations who responded to the question about award/grant administration (37/46) report that COVID-19 impacted the way that their organization awards and administers research awards and/or grants. The fact that many researchers could not access their labs was a driving force for many of the adaptations made. The most reported change was the provision of no-cost extensions (NCEs), including the automatic application of NCEs. Other changes include allowing for electronic signatures, e-payments, and other paperless administrative functions. Many also reported flexibility in shifting timelines, including application deadlines and grant terms. Due to the decline in available funds, some organizations reported reducing the number of new awards, and even cancelling an entire request for application (RFA).

At the time of this survey, only 8% of organizations reported that COVID-19 related changes or adaptations would remain permanently. Most respondents reported that the changes either would not continue beyond the pandemic, or that they did not know if the changes would continue.
Less than a quarter of respondents (24%) reported that their organization allowed grant funds to be used in new ways in 2020. 48% reported that their organization has not allowed grant funds to be used in new ways. Of the 24% who reported that funds were allowed to be in new ways, the most common change was allocating funds toward COVID related expenses and research activities. Other changes included reallocating travel funds, shifting funds toward salary support, and for childcare.

“Has your organization allowed grant funds to be used in new ways during COVID-19?

- Yes 24%
- No 48%
- Don’t know 7%
- No Response 21%

New COVID-19 Programs
43% of organizations surveyed report that they have funded new COVID-19 specific research. This includes donations as well as grants. Some organizations allocated additional, separate funds for COVID-19-related activities, and issued separate RFAs. Fewer organizations reported expansions to existing awards related to COVID-19. Among those who did not allocate new funds to COVID-19, a desire to not stray from the organization’s core mission was cited.

“...Our organization has allowed grant funds to be used in new ways during COVID-19 but only on a limited basis. Supplemental funding was offered to active grantees with the purpose of filling budgetary gaps resulting from the research slow down or shutdowns. A small number of grantees had the opportunity to add COVID-19 related work so we allowed using of a small part of the grant toward that purpose.”
- HRA Member

“...Our organization did not launch a COVID-19 research program but offered supplemental funding to current grantees as a result of COVID-19. The purpose of the supplement was to make up for lost time or to cover budgetary gaps resulting from the pause in research activities. The scope of Data Sharing grants, already offered before the pandemic, was broadened so grantees could use the funds to share COVID-19 relevant data in addition to research data from their funded project.”
- HRA Member
Allocation of Funds to Research

**Endowments**
Only one organization reported that the percentage of funds allocated to research decreased. Others report that while initial budget amounts were decreased or reallocated, after the stock market recovered budget amounts were restored, or even increased.

“At first, budget was decreased. As the stock market recovered, each program is allowed normal pre-pandemic number of grant allocations.” – HRA member

“When the markets fell, we were conservative and cut some grant funding to ensure the endowments did not go in the red.” – HRA member

**Fundraising**
58% of fundraising organizations reported that the percentage of funds allocated to research either increased (2) or stayed the same (16). 29% of respondents (9) reported a decrease in the percentage of funds allocated to research.

“Temporarily decreased percentage of funds for grants until fundraising activity recovers” – HRA member

“Even if we did not change the percentage of funds allocated, we ended up spending less money on grants. This was because we received fewer applications and proposals. Some labs were not able to submit proposals, all of them required a longer timeline to activate their grants.” – HRA member

**Societies/Other**
77% of respondents reported that their percentage allocation of funds to research did not change.
3. FUNDRAISING REVENUES

The top organizational impact of COVID-19 reported by fundraising organizations was the impact on fundraising revenues. 50% of fundraising organizations surveyed reported that the total amount of funds raised in calendar year (CY) 2020 decreased compared to CY 2019. The average reported decline in total revenues was 35% YOY. This amount is inclusive of Paycheck Protection Plan (PPP) loans received. 61% of fundraising organizations reported that they had applied for and received a PPP loan in the first round in 2020. Of these, 55% already had their loan forgiven at the time of this survey. Another 27% expect their loan to be forgiven. A few (4) organizations reported that their fundraising revenues increased, due to large gifts or other one-off events such as the sale of assets.

**Causes of Decreased Revenue**

94% of fundraising organizations who experienced a significant (>5%) decrease in funds cited the cancellation of in-person events as the primary cause. 84% of Fundraising organizations report that they implemented new fundraising tactics because of COVID-19 (i.e., use of new digital platforms, strategies or activities that had not been previously planned).

**Fundraising by the Numbers**

<table>
<thead>
<tr>
<th>Percentage of fundraising organizations surveyed who report a decrease in YoY total funds raised.</th>
</tr>
</thead>
<tbody>
<tr>
<td>50%</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Average reported year-over-year (2019 to 2020) decrease in funds among fundraising organizations (n=19).</th>
</tr>
</thead>
<tbody>
<tr>
<td>35%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Percentage of fundraising respondents who cite a lack of in-person events as the primary cause for their decline in 2020 fundraising revenue.</th>
</tr>
</thead>
<tbody>
<tr>
<td>94%</td>
</tr>
</tbody>
</table>

“**All in-person run/walk events, team endurance events and most in-person third party events were canceled or moved to a virtual platform. This resulted in a 60% decrease in events related revenue.**”

- HRA Member
Mitigation Strategies

72% of respondents report that their organization implemented new fundraising tactics because of COVID-19. However, new activities were largely focused on shifting previously in-person activities to a virtual format. The overall fundraising mix (relative contributions from each fundraising strategy/platform) did not shift significantly for most organizations. Members leveraged online platforms to host virtual events including virtual walks, galas, and online auctions. Members also report increasing their use of social media platforms such as Facebook and using gift apps for online donations.

To what extent did your fundraising mix change in 2020 compared to 2019? (Fundraising mix refers to the relative contributions of each fundraising strategy/platform)

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""Not much change other than shifting to virtual events and relative increase in industry grants, mostly for COVID related education."
- HRA Member

""We went virtual with all our in-person fundraising events, including walks and galas."
- HRA Member
Shifts to Online Strategies are Expected to Extend Beyond COVID-19

39% of organizations reported that they are making/have made permanent changes to their funding strategy. Changes that will persist beyond the pandemic mostly center on leveraging virtual platforms include including adding virtual options for in-person fundraising activities to draw a larger audience; virtual meetings with donors; and more digital engagement.

“Virtual events will be available moving forward so more people can attend regardless of location (hybrid in-person and virtual).”
- HRA Member

Will these changes to your fundraising strategy be maintained beyond the pandemic?

<table>
<thead>
<tr>
<th>Response</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, we are making/have made permanent changes to our funding strategy</td>
<td>14</td>
</tr>
<tr>
<td>Yes, but not permanently</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Don't Know</td>
<td>13</td>
</tr>
<tr>
<td>No Response</td>
<td>5</td>
</tr>
</tbody>
</table>
CONCLUSIONS & NEXT STEPS

Based on the findings and lessons learned from this evaluation, we offer the following set of recommendations:

CONCLUSIONS

1. **Flexibility is Most Important**
   At the end of the survey, respondents were asked to give advice to their peers. The most common advice (41%) was around the importance of organizational adaptation and flexibility. Flexibility in how grants/awards are administered, in WFH arrangements, and in fundraising strategies have all been of critical importance.

2. **Widespread Changes to Staffing and Organizational Structures were not Reported**
   **Reorganization:** The research team and steering committee had hypothesized that members may have undergone a reorganization (e.g., shutting down or selling divisions, replacing management, cutting budgets, and laying off workers) because of COVID-19. However, only eight (8) organizations out of 62 reported that they had gone through a reorganization. Of these seven (7) were fundraising organizations. The reorganizations consisted mostly of staff layoffs and budget cuts across the board.
   **Restructuring:** The research team and steering committee had hypothesized that members may have undergone a restructuring (e.g., a change in the structure or ownership through a merger or consolidation, spinoff acquisition, transfer, recapitalization, a change in name, or a change in management) because of COVID-19. Only one organization (fundraising) reported that this had occurred. 74% of survey respondents report that this was never discussed.

3. **The Impact of COVID-19 was not Overwhelmingly Negative (nor Positive)**
   Despite the significant impacts on fundraising revenues, only four (4) fundraising organizations characterized the overall impact of COVID-19 on their organization as “Very negative.” 31% pf organizations characterized the impact as negative, 11% as having a neutral impact, and 16% reported that COVID-19 had an overall positive impact on their organization. Respondents noted that this question was particularly difficult to answer as some aspects of COVID-19 were negative (decrease in funds raised, staff cuts) while others were positive (embracing more flexible work arrangements, endowment growth, and innovations that are likely to benefit the organization beyond the pandemic).

   “Having patience and understanding is key. Research might slow due to COVID restrictions, and the overall landscape may look slightly different. Use this as an opportunity to think differently about past paradigms and come up with novel solutions.”
   - HRA Member
4. Different Experience for Fundraising vs. Endowment
While the reported impact of remote and teleworking was consistent across organization types, for most other impacts results differed significantly based on funding model. Organizations that rely on fundraising reported more significant negative impacts than organizations that operate through an endowment. The cancellation of in-person fundraising events resulted in a significant loss of fundraising revenues in 2020. Conversely, the stock market performed well (achieving record highs) at the end of 2020, benefitting endowment organizations. However, the full extent of these impacts has not been fully realized across HRA’s membership as 45% of members (n=49) report that they operate on a fiscal year that differs from the calendar year.

NEXT STEPS

Track Progress Over Time
98% of members are open to repeating the survey, and most wish for it to be repeated in one year. This timeframe should elucidate adaptations that have become permanent, and account for different fiscal years to allow HRA to see the full impact of COVID-19 across its membership. The next survey would benefit from surveying at two levels within member organizations. Surveying at both the executive level and mid/junior level will support or refute the hypothesis that many opinions (especially around the impact of WFH and workplace culture) are driven by level of seniority. Given the widely reported impacts on women during the pandemic, it would also be useful to disaggregate responses by gender and/or to ask questions specific to employee impacts by gender.
**Answer Members’ Questions**
At the end of the survey, members were asked what questions they have for their peer organizations. The top for categories and illustrative questions are listed below.

- **WFH:**
  - How are they handling return to work in post-covid era?
  - How are you managing employees who are just not as productive or are just not handling tele-commuting?
  - How they are navigating discussions about potential return to work, and dealing with continued uncertainty?
  - What are effective strategies for onboarding new staff and introducing them to your organizational culture?
  - How many organizations that were forced to remote working plan to maintain a remote or hybrid work environment and what changes they have or plan to make to mitigate many of the challenges in communications and workplace dynamics that we faced during the pandemic.
  - What does a long-term hybrid in-person and remote solution look like for you for both office work and collaboration meetings?
  - Will other funders go back to in person review meetings (some or all) or have they found the expense and burden on reviewers is not worth the added benefits?

- **Strategic Planning:**
  - Are you revisiting your strategic plan due to the crisis?
  - How are you approaching planning for the coming FY and beyond?
  - What assumptions are you making about travel and in-person events?
  - How do you deal with grantees who needed to pause research but continue to pay staff in order to keep them for when in-lab research resumed?
  - No-cost extensions are one thing, but what about extra cost extensions?

- **Virtual Fundraising:**
  - Can organization survive with only virtual fundraising?
  - What are some success stories of converting from in-person to virtual events?
  - Will all events need to be hybrid going forward?

- **Mental Health:**
  - Are you worried about the mental well-being of your funded scientists and, if so, what are you doing about it?
  - How they have been intentional about fostering positive organizational culture during the pandemic?
APPENDICES
## APPENDIX 1: FOCUS GROUP DISCUSSION PARTICIPANTS

<table>
<thead>
<tr>
<th>Attendee Name / Position</th>
<th>Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fundraising, Wed 1/20</strong></td>
<td></td>
</tr>
<tr>
<td>Jill O’Donnell-Tormey, CEO/Director Scientific Affairs</td>
<td>Cancer Research Institute</td>
</tr>
<tr>
<td>Michael Kaplan, President/CEO</td>
<td>Melanoma Research Alliance</td>
</tr>
<tr>
<td>Michael Osso, President/CEO</td>
<td>Crohns Colitis Foundation</td>
</tr>
<tr>
<td>William (Bill) Phelps, Senior Vice President</td>
<td>Cancer Research Society</td>
</tr>
<tr>
<td>Louis Degennaro, President/CEO</td>
<td>Leukemia + Lymphoma Society</td>
</tr>
<tr>
<td>Yung Lie, President/CEO</td>
<td>Damon Runyon Cancer Research Association</td>
</tr>
<tr>
<td><strong>Endowment, Thurs 1/21</strong></td>
<td></td>
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<tr>
<td>Anne Hultgren, Executive Director</td>
<td>Arnold and Mabel Beckman Foundation</td>
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<tr>
<td>Euan Robertson, COO</td>
<td>Simons Foundation</td>
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<tr>
<td>Lynne Garner, President/Co-Trustee</td>
<td>Donaghue Foundation</td>
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<tr>
<td>Louis Muglia, President/CEO</td>
<td>Burroughs Wellcome Fund</td>
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<tr>
<td>Jeremy Smith, President</td>
<td>Rainwater Charitable Foundation</td>
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<tr>
<td><strong>Societies, Thurs 1/21</strong></td>
<td></td>
</tr>
<tr>
<td>Nancy Daly, CEO/Executive Vice President</td>
<td>Conquer Cancer</td>
</tr>
<tr>
<td>Eileen Melnick, Director of Grants &amp; Awards</td>
<td>Conquer Cancer</td>
</tr>
<tr>
<td>Caroline Best, Director of Research</td>
<td>American Urology Association</td>
</tr>
</tbody>
</table>
APPENDIX 2: FOCUS GROUP DISCUSSION NOTES

DISCUSSION NOTES

Cross-cutting

Key themes:
- Remote work / virtual engagement
- Diversity and inclusion
- Grant flexibility

Remote Work: A number of similarities emerged across the three focus group discussions. One of the most noteworthy – and one that underpins nearly all other organizational impacts of COVID-19 – has been the shift to remote work experienced by all member organizations since the onset of the pandemic. While there have been some differences in the way the virtual operating environment has impacted different types of organizations (mainly financial), from an operational perspective, all organizations are struggling with both the internal and outward facing challenges of operating in a remote environment.

Remote work and virtual engagement have presented universal difficulties across the organizations interviewed, but they have also given organizations the opportunity for critical reflection on matters of flexibility, inclusion and diversity. Internally, many are grappling with whether and how to continue more flexible or fully remote work policies for employees beyond the pandemic. While only a few noted specific challenges with employee productivity, most were more generally concerned with the possible implications of current and continued remote work on a lack of employee oversight (including gauging both performance and satisfaction), the need to foster open communication and collaboration, and maintaining organizational culture. This was arguably the line of inquiry with the greatest level of interest among FGD participants. They are incredibly keen to know how other organizations are handling the remote environment and if/how they are developing more formal policies and criteria for flexible work into the future.

Virtual Events: The shift in major events – conferences, in particular – and scientific review committees to a virtual format was another particularly challenging endeavor for most organizations. While there has been a learning curve and other expected pain points associated with these shifts, nearly all noted the ability for greater inclusion and diversity that they’ve achieved through virtual engagement during the pandemic. Many remarked on – or openly agreed with – the unnecessary costs (both financial and environmental) of holding so many events in person. One example given included the tradition of flying new grantees out to their headquarters for an award ceremony. All organizations maintain that face-to-face interactions are invaluable in many respects, they have come to recognize and reflect on the positive impacts of virtual convenings and outreach, and plan to make more permanent shifts to host more hybrid or entirely virtual events. They are interested in how other organizations have managed external virtual engagement and how they plan to continue to integrate virtual engagement in their outreach moving forward.
Grant Flexibility: In terms of grant awards and distribution, virtually all organizations triggered no cost extensions to their current grantees. There was no discernible consistency among organizations that added new COVID-19 related activities. Many did not have funding or did not see COVID-19 as relevant enough to their core mission to redirect funds. There was, however, serious concern across groups about the generally stalled nature of research and lack of new opportunities in many fields. In particular, participants expressed concern about the impact this might have on the careers and professional development of young investigators.

Of interest across the three groups was innovations and adaptations in the use and distribution of grant funds, as well as – and as a response to reflections on community diversity and inclusion – the potential for opening up the criteria for research grant applicants (e.g. allowing applicants not associated with academic institutions). Organizations would like to know whether other organizations have considered and/or implemented more inclusive grant-making policies.

Prevailing Questions:
- How are organizations dealing with the still looming uncertainty around the future of COVID and lack of certainty enabling concrete organizational decisions or longer-term strategy (especially regarding remote work)?
  - How did fundraising organizations approach the decision to tap into reserves? Has this guidance been codified?
- What impacts have we experienced that we can hopefully prevent or mitigate as organizations in the face of a future pandemic (or similarly disruptive event) and how?
- What have been the positive impacts/outcomes for organizations as a result of the pandemic?
- What new organizational policies have been created to protect organizations in the face of paused research activities? How are organizations dealing with grant extensions (especially because so many are now approaching the end of their given / reasonable extension period) and pivots to research to allow for continued work?
- How do we keep employees, donors, and grantees/researchers engaged in a remote or hybrid environment? How do we continue to network and maintain/grow relationships?
- What are the potential longer term and reverberating impacts that organizations are expecting in the out years?

The sections below discuss the effects and adaptations discussed in the FGDs that were more specific to the different organization types.

Fundraising organizations
As expected, organizations whose revenues come entirely from fundraising faced more significant challenges in the face of COVID-19. Organizations that rely more heavily on funding from peer-to-peer and events-based fundraising channels were hit particularly hard. These organizations were forced to downsize their workforces and cut other overhead expenses (e.g. giving up the organization’s office lease). While some were able to pivot and develop new or improved virtual giving platforms to better enable individual giving, these efforts did not cover the overall deficit. Events were also rather difficult to remake in a virtual format, and even
resulted in additional losses (although cushioned by insurance) for organizations that had already spent capital on event preparations prior to shutdowns.

The majority of Fundraising FGD participants indicated that they did not develop new fundraising strategies, per se, but “leaned in” to existing funding streams. This included focusing more time on communications and outreach to mid- and large-sized donors, requesting unrestricted donations to enable greater flexibility, and emphasizing the continued importance of their organizations health-focused missions in respect to and beyond the COVID-19 pandemic.

In terms of organizational programming, a majority of the organizations in this group were forced to make some changes or cuts to account for funding declines. This included elimination of training programs. Only one organization in this group mentioned adding new COVID-19 related programming. However, two organizations indicated that they actually extended additional funding to fellows to ensure positive and continued professional growth of the young professionals in their research communities. The stagnation of professional growth and development opportunities was a concern shared by all.

**Fundraising - Timeline**
Another important determinant in a fundraising organization’s ability to adapt to COVID-19 is the timing of their fiscal year. Organizations with a fiscal year beginning July 1 were commencing their annual budgetary planning and strategy processes when the pandemic hit. This allowed them to more effectively plan – albeit imperfectly given the high levels of uncertainty in the early months - for anticipated impacts, including revenue hits and lab closures, and to adapt their fundraising and programming strategies accordingly.

Since the timing of the fiscal year did impact organizations’ ability to plan, we suggest asking a question about the timing of respondents’ fiscal year. However, the vast majority of respondents across groups agreed that it would be most meaningful to collect data based on the calendar year since the unfolding of the pandemic is pegged to the calendar year.

**Endowment organizations**
Organizations operating on an endowment model were less impacted by COVID-19 than their fundraising or hybrid counterparts. In fact, with the exception of one organization, the FGD participants indicated that their organization’s endowments had experienced reasonable growth in the past year – outperforming previous years. One participant even remarked that their endowment was doing “embarrassingly well”.

Because of this financial stability, in addition to providing no-cost extensions to existing grantees (which the fundraising group did, as well), more organizations also reported creating new or additional grant opportunities for investigators who may have had funds from other organizations rescinded. There was also a higher prevalence of participants in this group whose organizations had added or repurposed funds for COVID-19 focused research activities.
While all groups discussed a relative degree of flexibility afforded to their grantees during this time (primarily in the form of no-cost extensions), this group also mentioned several instances of allowing grantees to repurpose funds to support personal changes experienced as a result of the pandemic (e.g. child care, other home support, etc.).

**Societies**
Financially, while the two organizations in attendance did experience some declines in revenue, they asserted that savings / cash reserves allowed them to absorb deficits and avoid layoffs or other significant cuts. Neither organization was forced to make staff cuts, though they did shift / reallocate staff according to increasing demands on certain departments. One organization has an existing endowment, while the other remarked on their current efforts to build an endowment to supplement direct cost donations (to “make awards whole”). The same organization is also moving away from costly and time intensive events and focusing on donors who can make “transformational gifts”. Both took losses on their annual conferences which are usually important revenue generators. One implemented a COVID-19 related fundraising campaign that was overwhelmingly successful.
APPENDIX 3: FOCUS GROUP DISCUSSION GUIDE

Total time: 90 minutes [Endowment; Fundraising] OR 60 minutes [Societies]

PART A: INTRODUCTION AND CONSENT (5 minutes)

Welcome. Thank you for joining us today. My name is Jenna White, and I am joined by my colleague Megan McDermott. We are independent researchers working with the Health Research Alliance (HRA) to conduct a survey of HRA members to better understand the organizational impacts of COVID-19. In particular, we plan to explore the impacts of COVID-19 on members’ revenues, operations, research grant awards, and programming.

Today’s discussion will inform a survey that will be sent out to all members mid-February. HRA plans to use the survey as a means to quantitatively and qualitatively document and communicate the impacts of the COVID-19 pandemic on member organizations. To that end, we have two objectives today:

1) To assess the degree to which our proposed lines of inquiry resonate with your organizations
2) To identify any additional areas of inquiry that are of interest to this group that should be considered for inclusion in the survey

To summarize, our goal today is to ensure we are asking the right questions in the survey that we plan to administer rather than to comprehensively answer those questions today.

In today’s session, you have been gathered together because you each are affiliated with an organization that operates through an [endowment/fundraising/society] model. If this does not describe your organization, please let us know. [Pause to ensure everyone is in the right place.]

Today’s session is confidential, meaning your responses will only be used by the research team and will be shared only in aggregate. We will not attribute any comments directly to you in our report or our discussions with HRA without your permission. In order to aid our notetaking, we would like to record this session for the use of our research team only. If at any point you would like us to pause the recording, please let us know via a direct message in the chat.

Following the administration of the survey and some additional targeted follow-up with members, we will write a report and submit it to HRA. We will also prepare a summary of key findings, which HRA will be able to share with this group. If you have any questions about this research, you can contact me or Maryrose Franko at any time.

Do you have any questions? Do you consent to participate? If not, please feel free to exit the call now before we begin the discussion.

PART B: PARTICIPANT INTRODUCTIONS (15 minutes)
1. Please introduce yourself and tell us your name, organization, role, and a brief description of how COVID-19 has impacted your organization (just a few sentences).

2. Let’s take a poll. In which area(s) has your organization been impacted most by COVID-19?

- Revenues (e.g., fundraising/endowment performance, revenue diversification)
- Operations (e.g., staff changes, restructuring, impact of remote work, other bottom-line adaptations)
- Research grant awards (e.g. number of awards, extensions, diversity of awards)
- Programming (e.g., conversion to virtual, cancelling, introducing new programming)
- Other

[Use voting feature in Zoom, preload with options – revenues, operations, research grant awards, programming, other]

3. Review Results. If you selected Other, would you like to comment? Any other comments?

PART C: DISCUSSION OF IMPACTS BY TOPIC (40 Minutes ~10 per topic)

4. Starting with the topic that received the most votes:

   a. Let’s hear from a few of you. Who’d like to share how COVID-19 impacted your organization’s [Revenues / Operations / Research Grant Awards / Programming / Other]
   b. Did anyone else have a similar experience? A different one?
   c. Was anyone able to overcome challenges in this area? If so, how?
   d. Is this an ongoing challenge? What barriers persist to overcoming this challenge?
   e. What would you like to know about how your peers are handling this challenge?

PART D: DISCUSSION ON ADAPTATIONS & BEST PRACTICES. (15 minutes)

5. I want everyone to reflect for a moment. What are the adaptations your organization has made in response to COVID-19 that have been the most impactful? Why are these significant?

   Let’s hear from a few of you. Who’d like to share?
   ......
   Did anyone adopt similar adaptations/practices?
   ......
   Were these adaptations formalized in any way? Will they continue beyond the pandemic?
PART E: SUMMARIZING REFLECTIONS (10 minutes)
6. In one sentence, what is the biggest impact COVID-19 has had on your organization? Please take a moment to consider, and write it in the chat box. [Discuss]

7. In one sentence, what is the most impactful action your organization has taken to mitigate the organizational challenges of COVID-19? Please take a moment to consider and write it in the chat box. [Discuss]

8. In one sentence, what would you like to know about how COVID-19 has impacted your peers? Please take a moment to consider and write it in the chat box. [Discuss]

9. In one sentence, what would you like to know about how your peers’ response to these challenges? Please take a moment to consider and write it in the chat box. [Discuss]

PART E: WRAP UP (5 minutes)
10. General survey feedback
- POLL: Have you participated in other surveys or research projects related to impact of COVID-19 on your organization?
  o Yes
  o No
- How much time are you/your team willing to invest in this survey and what will make it most useful to you/your organization?

11. Is there anything else you wanted to share today? Do you have any questions you’d like to ask others in the group?

Thank you for your time. If you have any additional thoughts after this session that you’d like to share, or if you have questions about the research, please feel free to be in touch. As I mentioned, we will be administering a survey to all HRA members, including everyone in this group, in February. The survey will serve as the basis for a report that will be shared in April. This session has been extremely useful for informing our research, and we hope you found it interesting as well.
HRA COVID-19 Impact Survey_March 2021

Introduction
HRA is conducting a broad landscape analysis on the impact the COVID-19 pandemic has had on nonprofit funders of biomedical research. This survey will give our membership a more complete picture of the affects the pandemic has had on the research community in 2020, as well as the anticipated impacts far beyond 2020.

All of the information you share in this survey will remain confidential. Your responses will only be used by the research team and will be shared only in aggregate. Your participation is completely voluntary. You may skip questions or opt out at anytime.

We encourage participants to engage other members of your organization as necessary to ensure full and accurate information. You can access the survey over multiple sessions and can edit your answers until you click "done" at the end of the survey.

You will receive a copy of the final report containing findings from this survey in April 2021. If you have any questions about this effort, please contact Maryrose Franko (maryrose@healthra.org).

Thank you for your support!

* 1. Please enter your contact information:

   Name
   Organization
   Email Address
2. Please select the top 3 ways COVID-19 has impacted your organization.

<table>
<thead>
<tr>
<th></th>
<th>1 - Biggest Impact</th>
<th>2 - 2nd Biggest Impact</th>
<th>3 - 3rd Biggest Impact</th>
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<tbody>
<tr>
<td>Fundraising Revenues</td>
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<tr>
<td>Endowment Performance</td>
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<td>Remote / Tele-work</td>
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<td>Organizational reorganization and/or restructuring (including layoffs and furloughs)</td>
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<tr>
<td>Research/grant awards and associated activities (review meetings, disbursement, extension, use, etc.)</td>
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<tr>
<td>Non-Research Programming</td>
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<tr>
<td>Uncertainty impacting our ability to plan for the future</td>
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<tr>
<td>Other</td>
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☐ Other (please specify)

3. Which of the following best describes your organization?

☐ Fundraising-based financial model (at least 80% of funds)

☐ Endowment-based financial model (at least 80% of funds)

☐ Other/society model
Endowments

This page asks about the impact of COVID-19 on your organization's research funding. To ensure we can make meaningful comparisons across organizations, all questions will refer to calendar years. I.e. January - December 2020 or January - December 2019.

4. How much did your organization spend on research awards/grants in each of the last 3 calendar years?

Jan - Dec 2020 Spend

Jan - Dec 2019 Spend

Jan - Dec 2018 Spend

5. How much do you anticipate spending on research grants/awards in calendar year 2021?

6. Did your organization's endowment grow in 2020?
   - Yes
   - No
   - Don't know
   - Prefer not to answer

7. Did your organization utilize additional endowment funds or other assets in 2020 (over what was planned/budgeted prior to COVID-19)?
   - Yes
   - No
   - Don't know
   - Prefer not to answer
   - N/A
Fundraising
This page asks about the impact of COVID-19 on your organization's research funding and your ability to fundraise. To ensure we can make meaningful comparisons across organizations, all questions will refer to calendar years. i.e. January - December 2020 or January - December 2019.

8. How much did your organization spend on research awards/grants in each of the last 3 calendar years?

Jan - Dec 2020 Spend
Jan - Dec 2019 Spend
Jan - Dec 2018 Spend

9. How much do you anticipate spending on research grants/awards in calendar year 2021?

10. Overall, did the total amount of funds raised by your organization in calendar year 2020 change compared to calendar year 2019 (inclusive of PPP loans or other COVID-19 related grant or loan income)?

☐ Yes - Increased
☐ Yes - Decreased
☐ No - Total funds raised did not change significantly (+/- 5%)
☐ Don't know
☐ Prefer not to answer
11. By what percentage did your total funds increase year-over-year from 2019 to 2020?

- 0% (No Change)
- 50%
- 100% (Doubled or more than doubled)

12. Please describe how/why your total funds increased.
13. By what percentage did your total funds decrease year-over-year from 2019 to 2020?

0% (No Change) 50% (Only raised half the amount as in 2019) 100% (We raised no funds)

14. Please describe how/why your total funds decreased.
15. Did your organization implement any new fundraising tactics as a result of COVID-19? (I.e. platforms, strategies or activities that you had not planned to implement)

☐ Yes ☐ No

☐ Don't know

☐ Prefer not to answer

16. If yes, please describe any new fundraising tactics implemented by your organization.


17. To what extent did your fundraising mix change in 2020 compared to 2019? (Fundraising mix refers to the relative contributions of each fundraising strategy/platform)

☐ A great deal ☐ A little

☐ A lot ☐ None at all

☐ A moderate amount

18. If applicable, please describe why/how your organization changed its fundraising strategy and/or how your existing fundraising mix shifted.


19. Will these changes to your fundraising strategy be maintained beyond the pandemic?

☐ Yes, but not permanently ☐ N/A

☐ Yes, we are making / have made permanent changes to our funding strategy

☐ No

☐ Don't know

☐ Prefer not to answer
20. If applicable, please describe any changes to your fundraising strategy that will be/are likely to be maintained.


21. Did your organization use any of its financial reserves as a result of COVID-19?

☐ No - We never discussed this  ☐ Don't know

☐ No - We discussed this, but so far have decided not to do so  ☐ Prefer not to answer

☐ Yes
First Round of PPP Loans

The following questions refer to the first round of PPP loans only.

22. Did your organization apply for PPP loan in the FIRST round?
   - ☐ Yes
   - ☐ No

23. Did your organization receive PPP loan in the FIRST round?
   - ☐ Yes
   - ☐ No

24. Has your loan from the FIRST round been forgiven? If not, do you expect it to be?
   - ☐ Yes, it has been forgiven
   - ☐ No, but I expect it to be forgiven
   - ☐ No, and I do not expect it to be forgiven
   - ☐ Unsure
25. Have you, or do you plan to apply during the SECOND round of PPP loans?

☐ Yes - My organization has already applied to the SECOND round

☐ Yes - My organization has not yet applied yet, but plans to apply to the SECOND round

☐ No - My organization has not, and does not plan to apply to the SECOND round

☐ Unsure
26. Did COVID-19 impact the way your organization awards and administers research awards and/or grants? (E.g., moving to more paperless options, adjusting application deadlines, or applying automatic no-cost extensions)

☐ Yes
☐ No

27. If yes, please describe the changes that your organization made.

28. Will any of the changes to your organization’s research award/grant process as a result of COVID-19 continue beyond the pandemic?

☐ Yes, but not permanently (at least for now)
☐ Don’t know
☐ Yes, we are making / have made permanent changes to our policies
☐ Prefer not to answer
☐ No
☐ N/A

29. If Yes, please describe the changes that are, or are likely to be permanent.


30. Has your organization allocated funds to new programs (e.g. COVID-19 specific research) during COVID-19?

☐ Yes

☐ No

☐ Don't know

☐ Prefer not to answer

31. If yes, please describe.

32. Has your organization allowed grant funds to be used in new ways during COVID-19?

☐ Yes

☐ No

☐ Don't know

☐ Prefer not to answer

33. If yes, please describe.

34. Did your organization change the percentage of funds allocated to research as a result of COVID-19?

☐ Yes – increased

☐ Yes – decreased

☐ No

☐ Don't know

☐ Prefer not to answer
35. If yes, please describe.

36. Has your organization changed the type of grants/awards offered as a result of COVID-19?
   ☐ Yes
   ☐ No
   ☐ Don't know
   ☐ Prefer not to answer

37. If yes, please describe.
38. Has your organization made changes to its research programming as a result of COVID-19? Select all that apply.

- Yes - we had to cut programming
- Yes - we added COVID-19 related programming
- Other
- No - we have not made notable changes to our programming
- Don't know
- Prefer not to answer

39. If yes, please describe any other programming changes your organization made as a result of COVID-19.

40. If programming was cut, how did your organization determine which programming to cut?
Operations

On this page, we would like to understand if/how COVID-19 impacted your staffing, structure, and working arrangements (including remote work).

41. Has your organization’s staffing been impacted by COVID-19? (Please select all that apply)

- No - Our staffing has not changed due to COVID-19
- Yes - We had furloughs, hiring freezes, or partial reductions in hours due to COVID-19
- Yes - We eliminated staff positions due to COVID-19
- Yes - Our staffing was negatively impacted in other ways
- Yes - Our organization’s staffing increased
- Don’t know
- Prefer not to answer

42. If yes, please describe.

43. Did your organization undergo a reorganization (E.g. shutting down or selling divisions, replacing management, cutting budgets, and laying off workers) as a result of COVID-19?

- No - This was never discussed
- No - This has been discussed, but we have decided not to
- Yes - We went through/are going through a reorganization
- Don’t know
- Prefer not to answer

44. If yes, please describe.

45. Did your organization undergo a restructuring (E.g. a change in the structure or ownership through a merger or consolidation, spinoff acquisition, transfer, recapitalization, a change in name, or a change in management) as a result of COVID-19?

- No - This was never discussed
- No - This has been discussed, but we have decided not to
- Yes - We went through/are going through a restructuring
- Don’t know
- Prefer not to answer
46. If yes, please describe.

47. How has teleworking and remote work among your staff changed? (Note: teleworking refers to staff who live near an office and had/have the option to be physically present on-site. Remote work refers to staff who do not live near an office.)

<table>
<thead>
<tr>
<th>December 2020</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>December 2019</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

48. To what extent do you agree with the following statements about remote work / telework?

<table>
<thead>
<tr>
<th>Completely Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Don't know / Prefer not to answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>My organization was well prepared for the transition to remote work / telework.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / telework has had almost no impact on organizational performance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / telework has had almost no detrimental impact on individual performance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / tele-work has presented almost no challenges.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My organization has a clear remote work / telework strategy.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remote work / telework has not changed our organizational culture.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

49. Please describe the impact of COVID-19 on your organization's approach to remote work and teleworking.
50. Did your organization reduce its footprint in 2020?
☐ Yes - We sold office space and/or land that we own
☐ Yes - We reduced the amount of office space that we lease No -
☐ No - We did not, and have no plans to reduce our footprint
☐ No - We did not reduce our footprint in 2020, but are currently discussing this No - We
☐ increased our office space (via either purchase or lease)
☐ Don't know
☐ Prefer not to answer

51. Did your organization introduce any other voluntary cost-cutting measures in 2020?
☐ Yes
☐ No
☐ Don't know
☐ Prefer not to answer

52. If yes, please describe your organization's voluntary cost-cutting measures.

53. Please describe any involuntary changes that resulted in cost-savings in 2020.

54. Are there any adaptations your organization made to its operations that you think were particularly beneficial?
☐ Yes
☐ No

55. If yes, please describe the adaptations.
56. Will any of these adaptations continue beyond the pandemic?

☐ Yes, for the foreseeable future ☐ Don’t know
☐ Yes, we are making / have made permanent changes to our policies ☐ Prefer not to answer
☐ No

57. Overall, how has COVID-19 impacted your organization?

☐ Very positively ☐ Very negatively
☐ Positively ☐ Don’t know
☐ No impact ☐ Prefer not to answer
☐ Negatively

58. Please summarize the overall impact COVID-19 had on your organization.
59. What has been your organization’s biggest challenge during COVID-19?

60. What is one piece of advice you would give to other funders of health research to help them mitigate the organizational impacts of COVID-19?

61. What question(s) would you like to ask your peer organizations?
The demographic information requested below will assist us in uncovering trends among the responses.

62. Which of the following best characterizes your organization’s fiscal year?
   - Same as the calendar year (January - December)
   - Different than the calendar year (e.g. July - June)

63. What is the approximate size of your organization?
   - 15 employees or fewer
   - 16-50 employees
   - 51-100 employees
   - 101 - 500 employees
   - 501 - 1000 employees
   - 1000+ employees

64. What was the size of your annual budget in your last full fiscal year prior to COVID-19? (Note: this information will only be used for demographic analysis purposes.)
65. When should we next repeat this survey?

- Never
- In 6 months
- In 1 year
- Other (please specify)
- Don’t know
- Prefer not to answer
66. May the research team contact you for additional information? (E.g. to gain more information about best practices.)

67. Is there anything else that you would like to share?

68. FEEDBACK: Is there anything else you would like us to ask in a future survey on this topic?
APPENDIX 5: SURVEY RESULTS

Responses: 62
Notes: Only one response per organization was allowed. Duplicate responses were removed, and the most recent/complete version of a response was used in the final dataset. Only responses that included information beyond demographic data are included in the response count of 62. Unless noted otherwise, all results are based on a count of 62, with non-responses for each question indicated.

BACKGROUND

Q 1. Please enter your contact information. (Note, only names of companies listed.)

<table>
<thead>
<tr>
<th>Organization Name</th>
<th>Organization Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alex's Lemonade Stand Foundation</td>
<td>Hydrocephalus Association</td>
</tr>
<tr>
<td>Alzheimer's Association</td>
<td>IRIDIAN GENOMES</td>
</tr>
<tr>
<td>American Association for Cancer Research</td>
<td>JDRF</td>
</tr>
<tr>
<td>American Brain Tumor Association</td>
<td>John Templeton Foundation</td>
</tr>
<tr>
<td>American Cancer Society</td>
<td>Kenneth Rainin Foundation</td>
</tr>
<tr>
<td>American Epilepsy Society</td>
<td>Leducq Foundation for Cardiovascular Research</td>
</tr>
<tr>
<td>American Federation for Aging Research</td>
<td>Lipedema Foundation</td>
</tr>
<tr>
<td>American Heart Association</td>
<td>LUNGevity Foundation</td>
</tr>
<tr>
<td>American Lung Association</td>
<td>Melanoma Research Alliance</td>
</tr>
<tr>
<td>Arnold and Mabel Beckman Foundation</td>
<td>Muscular Dystrophy Association</td>
</tr>
<tr>
<td>ASH</td>
<td>National Psoriasis Foundation</td>
</tr>
<tr>
<td>Autism Science Foundation</td>
<td>NET Research Foundation</td>
</tr>
<tr>
<td>Autism Speaks</td>
<td>Neuroendocrine Tumor Research Foundation</td>
</tr>
<tr>
<td>Breast Cancer Research Foundation</td>
<td>Ovarian Cancer Research Alliance</td>
</tr>
<tr>
<td>BrightFocus Foundation</td>
<td>Parkinson's Foundation</td>
</tr>
<tr>
<td>Burroughs Wellcome Fund</td>
<td>Pew</td>
</tr>
<tr>
<td>Cancer Research Institute</td>
<td>Rainwater Charitable Foundation</td>
</tr>
<tr>
<td>Children's Tumor Foundation</td>
<td>Rheumatology Research Foundation</td>
</tr>
<tr>
<td>Circle of Service Foundation</td>
<td>Rita Allen Foundation</td>
</tr>
<tr>
<td>Conquer Cancer, the ASCO Foundation</td>
<td>SCRF</td>
</tr>
<tr>
<td>Crohn's &amp; Colitis Foundation</td>
<td>Simons Foundation</td>
</tr>
<tr>
<td>CurePSP</td>
<td>St. Baldricks Foundation</td>
</tr>
<tr>
<td>CureSearch for Children's Cancer</td>
<td>The ALS Association</td>
</tr>
<tr>
<td>Damon Runyon Cancer Research Foundation</td>
<td>The Association for Frontotemporal Degeneration</td>
</tr>
<tr>
<td>Donaghue Foundation</td>
<td>The Gerber Foundation</td>
</tr>
<tr>
<td>Doris Duke Charitable Foundation</td>
<td>The Helmsley Charitable Trust</td>
</tr>
<tr>
<td>Fanconi Anemia Research Fund</td>
<td>The Mark Foundation for Cancer Research</td>
</tr>
<tr>
<td>Focused ultrasound foundation</td>
<td>The REAM Foundation</td>
</tr>
<tr>
<td>Foundation Fighting Blindness</td>
<td>The V Foundation for Cancer Research</td>
</tr>
<tr>
<td>Foundation for Physical Therapy Research</td>
<td>Tuberous Sclerosis Alliance</td>
</tr>
<tr>
<td>Health Resources in Action</td>
<td>W. M. Keck Foundation</td>
</tr>
</tbody>
</table>
### Q 2. Please select the top 3 ways COVID-19 has impacted your organization.

<table>
<thead>
<tr>
<th>Org Type</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
<td>Fundraising Revenues</td>
<td>Remote / Tele-work</td>
<td>Research/grant awards and</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>associated activities</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(review meetings, disbursement,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>extension, use, etc.)</td>
</tr>
<tr>
<td>Society/Other</td>
<td>Research/grant awards and</td>
<td>Remote / Tele-work</td>
<td>Uncertainty impacting</td>
</tr>
<tr>
<td></td>
<td>associated activities</td>
<td></td>
<td>our ability to plan for the</td>
</tr>
<tr>
<td></td>
<td>(review meetings, disbursement,</td>
<td></td>
<td>future</td>
</tr>
<tr>
<td></td>
<td>extension, use, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endowment</td>
<td>Remote / Tele-work</td>
<td>Research/grant awards and</td>
<td>Endowment Performance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>associated activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(review meetings, disbursement,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>extension, use, etc.)</td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>Remote / Tele-work</td>
<td>Research/grant awards and</td>
<td>Fundraising Revenues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>associated activities</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>(review meetings, disbursement,</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>extension, use, etc.)</td>
<td></td>
</tr>
</tbody>
</table>

### Q 3. Which of the following best describes your organization?

<table>
<thead>
<tr>
<th>Number of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fundraising</td>
</tr>
<tr>
<td>Endowment</td>
</tr>
<tr>
<td>Society/Other</td>
</tr>
</tbody>
</table>

Bar chart showing the number of respondents for each category.
### Endowments

4. How much did your organization spend on research awards/grants in each of the last 3 calendar years?

<table>
<thead>
<tr>
<th></th>
<th>Jan - Dec 2020 Spend</th>
<th>Jan - Dec 2019 Spend</th>
<th>Jan - Dec 2018 Spend</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average</strong></td>
<td>$46,368,299.58</td>
<td>$47,001,346.77</td>
<td>$43,645,330.08</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>$556,419,595.00</td>
<td>$611,017,508.00</td>
<td>$567,389,291.00</td>
</tr>
<tr>
<td><strong>Number of Responses</strong></td>
<td>12</td>
<td>13</td>
<td>13</td>
</tr>
</tbody>
</table>

5. How much do you anticipate spending on research grants/awards in calendar year 2021?

<table>
<thead>
<tr>
<th></th>
<th>Jan - Dec 2021 Anticipated</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average</strong></td>
<td>$49,434,460.17</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>$593,213,522.00</td>
</tr>
<tr>
<td><strong>Number of Responses</strong></td>
<td>12</td>
</tr>
</tbody>
</table>

6 & 7. How much do you anticipate spending on research grants/awards in calendar year 2021?

<table>
<thead>
<tr>
<th>Did your organization’s endowment grow in 2020?</th>
<th>Did your organization utilize additional endowment funds or other assets in 2020 (over what was planned/budgeted prior to COVID-19)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Don't Know / Unsure</td>
<td>3</td>
</tr>
<tr>
<td>No Response</td>
<td>2</td>
</tr>
</tbody>
</table>
8. How much did your organization spend on research awards/grants in each of the last 3 calendar years?

<table>
<thead>
<tr>
<th></th>
<th>Jan - Dec 2020 Spend</th>
<th>Jan - Dec 2019 Spend</th>
<th>Jan - Dec 2018 Spend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>$14,029,245.86</td>
<td>$19,737,054.44</td>
<td>$19,644,829.61</td>
</tr>
<tr>
<td>Total</td>
<td>$476,994,359.29</td>
<td>$14,390,374.00</td>
<td>$11,699,652.50</td>
</tr>
<tr>
<td>Responses</td>
<td>34</td>
<td>35</td>
<td>33</td>
</tr>
</tbody>
</table>

9. How much do you anticipate spending on research grants/awards in calendar year 2021?

<table>
<thead>
<tr>
<th></th>
<th>Jan - Dec 2021 Anticipated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>$16,514,102.04</td>
</tr>
<tr>
<td>Total</td>
<td>$13,033,916.67</td>
</tr>
<tr>
<td>Responses</td>
<td>32</td>
</tr>
</tbody>
</table>

10. Overall, did the total amount of funds raised by your organization in calendar year 2020 change compared to calendar year 2019 (inclusive of PPP loans or other COVID-19 related grant or loan income)?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes - Increased</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Yes - Decreased</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>No - Total funds raised did not change significantly (+/- 5%)</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Don't know</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>No Response</td>
<td>6</td>
<td>2</td>
</tr>
</tbody>
</table>

Q 11. By what percentage did your total funds increase year-over-year from 2019 to 2020?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>31.33%</td>
<td>16%</td>
</tr>
<tr>
<td>Responses</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

Q 12. Please describe how/why your total funds increased.

- We received larger bequests than usual
- 1- Sale of asset increased revenue; however, grassroots fundraising decreased by 36%
- The increased funds were mostly due to increased COVID-19-related patient services offered through the Foundation.
- Total funds have increased year-over-year, recently due to a large gift but also due to steady fundraising increases.

Q 13. By what percentage did your total funds decrease year-over-year from 2019 to 2020?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>34.72%</td>
<td>21%</td>
</tr>
<tr>
<td>Responses</td>
<td>19</td>
<td>1</td>
</tr>
</tbody>
</table>
Q 14. Please describe how/why your total funds decreased.

- Event cancellations due to COVID.
- All in-person run/walk events, team endurance events and most in-person third party events were canceled or moved to a virtual platform. This resulted in a 60% decrease in events related revenue.
- Inability to hold face-to-face events. Macroeconomic conditions and job loss.
- . Primarily we are seeing decreased year over year revenue in Special Events due to cancelations or a change in format, Bequests and Government Grants.
- Some of our fundraising events were unaffected, but we had to move one to all online (and decided not to charge, reducing revenue), and cancelled three, and then those individual donation levels dropped significantly.
- Primarily due to loss revenues from Corporate partners who had to reduce or not renew contracts
- Many of our events were either postponed or canceled with all of them going virtual. Thus we have to pivot and re-create our rules of engagement for participants and donors. Our Special Events, Endurance, and Major Gifts revenues were hit the hardest.
- Our fundraising model relies on the families affected by Fanconi Anemia to raise money. Due to the issues with COVID restrictions, they were not able to hold many of their in-person fundraising events.
- Our grassroots fundraiser held by students across the country was canceled accounting for the bulk of the loss over 2019. We also lost a number of corporate sponsors. Our board stopped all fundraising efforts for 3 months and even with staff urging it took time to ramp back up. They only agreed when they started seeing asks from other organizations in their mailbox and by then we were behind with print shops at capacity.
- Primarily a decrease in revenue from walks and special events that could not be held in person.
- Fundraising was down approximately 50%, largely due to JDRF’s prior fundraising model of events-based fundraising, which was suspended in 2020.
- [We] rely largely upon in-person events (galas, walks, golf tournaments, Firefighters "fill the boot") almost all of which have been canceled and are challenging to conduct virtually
  - reduced event revenue
  - Our fundraising model is mainly based on head shave events that typically take place in crowded pubs/bars. March is also our biggest fundraising month and March is when the closures started. The majority of fundraising events were canceled.
  - Impact of event fundraising in our chapter offices.
  - no in-person fundraising event; average donations decreased.
  - Cancellation of in-person events due to the pandemic
  - Revenue from special events (galas, walks) and major donations to our research campaign were down 50% compared to 2019.
  - Primarily decreased revenue from our Annual Meeting which was held virtually- reduced registration, reduced sponsorship
Q 15. Did your organization implement any new fundraising tactics as a result of COVID-19? (I.e. platforms, strategies or activities that you had not planned to implement)

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>26</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>2</td>
</tr>
<tr>
<td>No Response</td>
<td>5</td>
</tr>
</tbody>
</table>

Q 16. If yes, please describe any new fundraising tactics implemented by your organization.

- All virtual
- Many of our fundraisers went virtual utilizing Zoom and online auctions.
- Virtual events
- More digital stakeholder cultivation
- A virtual even in 2020, and moving to a facebook contained campaign addition in 2021 for first time.
- We turned many of our standard events into virtual events (virtual run, virtual Lemon Ball, virtual lemonade stands, etc).
- We transitioned all our in-person BT5K events to virtual events. In addition, we implemented several online fundraising events including a live concert and a virtual golf challenge. We utilized several new challenge grants in conjunction with “giving days” such as GivingTuesday.
- Changed special event format to virtual, when possible. Increased investment in individual giving.
- We are soliciting sponsorships for events to KEEP them online. WE are also making local events open to a larger audience and encouraging virtual participation. We have also changed our research funding priorities and are targeting different audiences.
- Pivoted to virtual events and they were reasonably successful.
- We created online live fundraising events including a virtual telethon for World NF Awareness Day, virtual walks, online streaming concerts, virtual gala, online poker, virtual cocktails, and virtual donor receptions, etc.
- Our use of online fundraising through social media platforms increased in 2020.
- We held virtual events and went back to a mobile giving option. Used email and social more to promote awareness. We also placed an emphasis on planned giving and that allowed conversations for IRA roll-over gifts to get cash now in addition to future commitments.
- Virtual comedy show Virtual walks 40-mile challenge (social media fundraiser with running) Express feedback for good
- All fundraising activities that could be, were conducted virtually (events, donor calls, etc).
- Some virtual versions of in-person events; strategic refocus on selling specific aspects of mission rather than general grassroots fundraising
- virtual events
- livestream of virtual headshave events. Streamed on social channels
- Virtual events in local communities
- automated matching gift app for online donations; encouraged virtual grassroots events
- "Walks" were held virtually and online silent auctions were added. Community-driven online fundraising activities (e.g., hot wings eating challenge) added tens of thousands of dollars.
- We planned many small virtual events that are links to fundraising
- Virtual fundraising events
• We went virtual with all our in-person fundraising events, including walks and galas.
• Fundraising events have now been held virtually.
• Virtual Gala. Pivot messaging around to funded research benefiting understanding of COVID
• We are not a fundraising organization, these programs are funded by Trusts and Foundations.
• Specific outreach to existing donors to support covid-related funding for our current scientists.
• Use of virtual events for fundraising.
• Moved to virtual platform for annual meeting, so industry funding moved to different modes as well
• We converted some of our events to virtual. We also created a COVID Impacts Cancer call to action to support resources for cancer healthcare professionals.

Q 17. To what extent did your fundraising mix change in 2020 compared to 2019? (Fundraising mix refers to the relative contributions of each fundraising strategy/platform)

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>None at all</td>
<td>0</td>
</tr>
<tr>
<td>A little</td>
<td>12</td>
</tr>
<tr>
<td>A moderate amount</td>
<td>7</td>
</tr>
<tr>
<td>A lot</td>
<td>3</td>
</tr>
<tr>
<td>A great deal</td>
<td>6</td>
</tr>
<tr>
<td>No response</td>
<td>8</td>
</tr>
</tbody>
</table>

Q 18. If applicable, please describe why/how your organization changed its fundraising strategy and/or how your existing fundraising mix shifted.

• All virtual
• we increased digital presence (online/cc donations)
• We submitted many more grants for corporate funding for both our research and medical education programs
• Not much change other than shifting to virtual events and relative increase in industry grants, mostly for COVID related education
• The mix changed slightly because most of the third-party events held on our behalf did not happen.
• More digital stakeholder cultivation / engagement throughout the year
• Event was down, online giving, and unanticipated gifts were up.
• With event revenue down significantly, our individual donors as well as corporate and foundation supporters generously increased or maintained their 2019 donation levels. We targeted our individual and foundation donors with special communications regarding the impact of covid-19 on our fundraising, how we were responding to the needs of our community during the pandemic and specifically asked them to increase their giving. We also saw growth in our corporate sponsorships for virtual mission related events as it provided companies with a broader/larger audience in which to market their product.
• Much greater reliance on virtual events; far fewer in-person events
• Decreased budget for special events. Increased budget for individual giving
• We are spending more time developing our individual giving campaigns since corporate giving has decreased.
• Our fundraising strategy changed in that we needed to heighten engagement in our virtual events to keep them interesting to our community, however, we enhanced our ability to steward and build stronger relationships because we could be virtual.
• As mentioned previously, we rely on in-person events predominantly. We had to shift our strategy to mostly online fundraising.
• Our calling program is usually led by two people - one trustee and one former president. With COVID some reluctant to participate in the past, got on board and we surpassed our budgeted goal for this program. In addition, we steered our nominating committee to only consider potential trustees willing to raise money and will bring on 3 new trustees in 2021.
• The majority of fundraising still came from major donors and through our walks.
• Fundraising shifted from events based revenue, to individual giving on a much greater scale.
• We shifted to a more strategic focus on selling specific aspects of mission rather than general grassroots fundraising as less staff required
• virtual events took on far more importance
• Greater emphasis on non-event activities, individual (including major gifts) and corporate giving
• no in person major fundraising event; more support for virtual grassroots events; more donations; average donation size decreased.
• We put more effort into email appeals and hybrid/virtual events.
• Special event fundraising was lower than budgeted, but 2019 was also an unusually high year (our 45th anniversary). In-person events were impossible, so we shifted to many more smaller online events. Fortunately, industry partnerships provided stronger funding in 2020 compared to 2019 (likely cyclical, not COVID-driven).
• We have regional groups of fundraisers (patients/caregivers) and we were able to reach outside of the geographical limit of these groups (for example - a south Florida-based fundraiser that was always done in person was done virtually and we could outreach to a national audience.
• Grassroot fundraising shifted from in person to virtual
• Our events did not perform well. On the other hand, our pharma support increased specifically to COVID-19-related programs.
• Less dependency on events

Q 19. Will these changes to your fundraising strategy be maintained beyond the pandemic?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, we are making / have made permanent changes to our funding strategy</td>
<td>14</td>
</tr>
<tr>
<td>Yes, but not permanently</td>
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</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Don’t Know</td>
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</tr>
<tr>
<td>N/A</td>
<td>0</td>
</tr>
<tr>
<td>No Response</td>
<td>5</td>
</tr>
</tbody>
</table>

Q 20. If applicable, please describe any changes to your fundraising strategy that will be/are likely to be maintained.

• as above - increasing methods of payment
• I think we will continue to have a virtual component for some fundraisers.
• Some virtual strategies may persist
• We will do more virtual meetings with donors to replace past travel and local gatherings.
• More digital engagement
• As we return to in-person events, we will continue to offer a virtual component in order reach more constituents. We plan to continue to grow our individual giving revenue stream with increased staffing, communication, and personal outreach. Donor Advised Funds will become a focus of our stewardship efforts as we look to increase this vehicle for giving. Corporate sponsorship package will contain a hybrid of in-person and virtual options to expand marketing outreach.
• While revenue for special events is expected to increase as we return to in-person format, we will continue to offer virtual options. Focus on individual giving will continue
• We are doing a mix of in person and online events, allowing for greater participation.
• continue to grow the major gift program.
• Our reinforced focus on stewardship will always remain, and we will continue to evolve the majority of our larger events to be both in-person and virtual to attract a larger audience and grow our revenue and donor base. Virtual events will remain, and all of our in-person events will have a virtual component or vice versa. And our ability to steward donors virtually will enhance our ability to increase our revenue across the globe.
• We will continue to do online fundraising but will also revert back to in-person events when we are able.
• We have been working for a number of years to create a culture of philanthropy on our board. 4 trustees will rotate off at year-end that were not comfortable and assisted very little. Three new trustees, with proven track records in fundraising, will start in Jan 2022. My hope is this will have others on the board step up and also provide new networks and opportunities for fundraising.
• Virtual events will be available moving forward so more people can attend regardless of location (hybrid in-person and virtual).
• Focus on fundraising around specific aspects of mission (supporting a program rather than organization as a whole)
• Greater attention to individual giving channels and corporate support
• Could convert some events to a hybrid model, part in person attendance, part remote.
• We will keep on developing virtual events to reach international audiences
• Virtual fundraising
• We will use a hybrid of in-person and virtual fundraising strategies.
• Virtual events are likely to continue.

| Q 21. Did your organization use any of its financial reserves as a result of COVID-19? |
|-----------------------------------------------|-----|-----|
| Yes                                           | 3   | 1   |
| No - We discussed this, but so far have decided not to do so | 11  | 1   |
| No - We never discussed this                   | 8   | 2   |
| Don’t know                                     | 7   | 1   |
| Prefer not to answer                           | 2   | 2   |
| No response                                   | 5   | 2   |
### PPP Loans

#### Q 22. Did your organization apply for PPP loan in the FIRST round?

<table>
<thead>
<tr>
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<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
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<tr>
<td>No</td>
<td>5</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>No Response</td>
<td>9</td>
<td>5</td>
<td>2</td>
</tr>
</tbody>
</table>

#### Q 23. Did your organization receive PPP loan in the FIRST round?

<table>
<thead>
<tr>
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<th>Societies</th>
<th>Endowment</th>
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</thead>
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<td>0</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>No Response</td>
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<td>5</td>
<td>7</td>
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</table>

#### Q 24. Has your loan from the FIRST round been forgiven? If not, do you expect it to be?

<table>
<thead>
<tr>
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<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, it has been forgiven</td>
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</tr>
<tr>
<td>No, but I expect it to be forgiven</td>
<td>6</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Unsure</td>
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<td>1</td>
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</tr>
<tr>
<td>No Response</td>
<td>14</td>
<td>7</td>
<td>15</td>
</tr>
</tbody>
</table>

#### Q 25. Have you, or do you plan to apply during the SECOND round of PPP loans?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes - My organization has already applied to the SECOND round</td>
<td>11</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>No - My organization has not, and does not plan to apply to the SECOND round</td>
<td>9</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Unsure</td>
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</tr>
<tr>
<td>No Response</td>
<td>9</td>
<td>5</td>
<td>17</td>
</tr>
</tbody>
</table>

#### Q 26. Did COVID-19 impact the way your organization awards and administers research awards and/or grants? (E.g., moving to more paperless options, adjusting application deadlines, or applying automatic no-cost extensions)

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>21</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>No Response</td>
<td>7</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>
Q 27. If yes, please describe the changes that your organization made.

- We made more wire transfers for grant payments. We have been considering more extension requests (our Charter has strict limitations that no grants can exceed 60 months in duration and most need to remain under 36 months) that are over 36 months in duration. We limited some of the funding areas that would receive open submission letters of intent in 2020. We are actively looking into ways we can sign grant agreements and other legal documents with electronic signatures instead of wet signatures.
- Provided no-cost extensions, adjusted timelines, and adjusted eligibility criteria.
- Liberal no-cost extensions; flexible use of previously granted funds; review calls and interviews moved entirely online
- Moved to e-payments for grants, shifted application funding cycle, cancelled a funding mechanism, offered additional funding to current grantees without applications, automatically awarded NCE to current grantees.
- Moving to all paperless operations, meetings moved to virtual formats, lenient on no-cost extensions.
- We allowed no cost extensions without exception to all awardees who applied. We allowed 10,000 of existing grant funds to go toward COVID emergency related expenses
- We removed all reporting requirements, including those required to receive grant payment, to ease the burden on organizations. We also allowed organizations to convert program-specific grants to general operating grants.
- Adjusted application and reporting deadlines as needed, offered flexible and simplified NCE requests, amended grants to allow flexibility in terms requiring research effort protection so grantees could temporary allocate more time to clinical work, allowed for budgeted personnel expenses to be charge to the grant even if the work had been paused. For new awards, offered deferred grant start dates. Grants management has been working toward more paperless options for a while. For example, signing of electronic grant agreements and electronic fund transfers were already in place.
- Granting more no-cost extensions and extending deadlines for progress reports and reviews.
- We made many no-cost extensions. We tightened our giving to make way for unplanned COVID-19 research grants. We adjusted our grant cycle timing to give researchers more time to complete proposals.
- Application deadlines adjusted, revised timelines for grants approved, revised deadlines for grant deliverables approved, Refunds accepted via ACH payment
- adjusting application deadlines, more flexibility with no cost extensions, electronic grant payments
- Delay in award start dates, fewer proposals funded, fewer funding opportunities available, increased approvals for no cost extensions
- Applying automatic no cost extensions
- Not many changes other than some flexibility around NCEs
- Automatic No cost extensions were given to grantees.
- We were much more flexible with deadline extensions, no cost extensions and rebudget requests. We also pivoted from face to face review to virtual.
- We ran very few new award cycles last year. We shifted everyone's payments and reporting by 6 months.
- We extended the application deadline for 2020 only. We increased grant term for our shortest grant from three months to four months in 2020 and may continue for 2021. Additionally, we were flexible with report deadlines and we granted more No Cost Extensions. For NCE's specifically
related to COVID, we did not require interim reports, which we typically require for NCEs. We allowed NCEs for one grant mechanism, which we hadn't allowed in previous years. Lastly, for grantees who were already in No Cost Extension during the pandemic, we offered second NCEs, which is generally not permitted by our policies.

- Very streamlined process for special COVID-19 no cost extension.
- Peer review meetings were all via conference calls; allowing more NCEs.
- We had to cancel in person review but we also cancelled an entire RFA.
- We reduced the amount of new awards to avoid having to deny funding of projects that had been approved for funding.
- One item we changed after seeing another HRA member comment on it was to have researchers sign off when they were able to get into the labs and resume work, holding funding until they were able to continue work. More communication with the researchers to see how they were doing. A survey was implemented to track.
- Decreased funding overall, didn't run most standard opportunities.
- Became very lenient with no-cost extensions, moved to monthly rather than quarterly grant payments, delayed some payments, paused applications for new grants, review sessions ad hoc or virtual.
- Changed (delayed) timeline for grant applications, granted far more NCEs.
- We adjusted deadlines and provided NCEs.
- Adjusting application deadlines, applying extensions in progress reporting.
- No change in awards; we are being more generous/lax with no cost extensions.
- More flexible with NCEs and start dates. Required confirmation that research team was able to start or continue the research before next payment was made.
- Covid specific no-cost extention.
- 1) Virtual study sections and progress report reviews  2) Courtesy NCEs  3) Electronic fund transfer process.
- We applied automatic no-cost extensions.
- Initially, deadlines needed to be adjusted due to the initial onset of the pandemic and institutions moving towards remote offices. NCEs have been allowed to be extended to accommodate further disruptions in research activities due to closures. We have also worked with some awardees to augment projects based upon feasibility to complete the work.
- We switched to quarterly need based payments.
- No-cost extensions and adjusting deadlines.
- Allowed e-signatures; offered no-cost extensions; offered support for virtual training opportunities/workshops.
Q 28. Will any of the changes to your organization’s research award/grant process as a result of COVID-19 continue beyond the pandemic?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
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</thead>
<tbody>
<tr>
<td>Yes, we are making / have made permanent changes to our policies</td>
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<td>1</td>
<td>1</td>
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<tr>
<td>Yes, but not permanently (at least for now)</td>
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<tr>
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<td>9</td>
</tr>
<tr>
<td>N/A</td>
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</tr>
<tr>
<td>No Response</td>
<td>7</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

Q 29. If Yes, please describe the changes that are, or are likely to be permanent.
- We are unsure, but will consider if grant selection meetings remain virtual in the future.
- ACH transfers for grant payments; not sure yet about other changes.
- Paperless payments.
- Virtual interviews may become a permanent change from flying out interviewees. Advisory committee members will still meet in person, but interviewees will be virtual.
- Unclear
- Looking for more projects utilizing already available data sets for the near future.
- Future peer review meeting formats will be TBD.
- Some reviews will continue to be online. We are bringing back our largest RFA and planning an in person 2022 meeting.
- We left the language broad to cover any disruption to the researchers work.
- We may stay with monthly grant disbursements--not sure about the rest.
- More funding for fellowships
- Unclear at this point. We have always been pretty flexible about NCEs and will probably continue to do that.
- We will probably have a hybrid of virtual and in-person scientific meetings. The doctors love it.
- While we’re not sure what the long-term impact may be, conferences we fund that have gone virtual may also continue to be held virtually.
- E-signatures permanent change. Likely to offer increased flexibility with virtual training/workshop support

Q 30. Has your organization allocated funds to new programs (e.g. COVID-19 specific research) during COVID-19?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
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<tbody>
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<tr>
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<td>14</td>
<td>4</td>
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</tr>
<tr>
<td>No Response</td>
<td>6</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
• We’ve made some donations in 2020 to support COVID-19 related work. And we will also be doing so in 2021. Some of our grants have also added components to their research related to COVID-19.
• During 2020 we made several grants to organizations in the journalism space re: covering the impact of COVID and in particular with a focus on communities of color
• no- We would not want to detour away from our mission.
• COVID related one time call for "COVID Collaboration grant opportunity. Small grants of $10,000 - $50,000 to enable launch of collaborative projects that have potential for near term impact in the current crisis. Must involve at least two BWF-associated investigators who have non-overlapping approaches and tool sets.
• Our Board allocated additional funds to COVID-19-related activities – e.g., supporting COVID-19 clinical data collection efforts, infrastructure for vaccine communications and dissemination, etc.
• Our organization did not launch a COVID-19 research program but offered supplemental funding to current grantees as a result of COVID-19. The purpose of the supplement was to make up for lost time or to cover budgetary gaps resulting from the pause in research activities. The scope of Data Sharing grants, already offered before the pandemic, was broadened so grantees could use the funds to share COVID-19 relevant data in addition to research data from their funded project.
• We funded COVID-19 research, clinical trials, awareness programs and prevalence studies
• RFA - Maternal COVID-19 as a potential risk for autism: supplemental funding for ongoing pregnancy cohorts
• We funded studies on vaccines and long term effects
• Reboot Fund - funds for current and alumni grantees who need funds because of setbacks related to pandemic
• COVID Rapid Response grants - $2.5M Diversity supplements to existing AHA awardees
• Bridge grants for COVID-19 related delays in research or hiring
• Some commitments (relatively small in the context of overall spend) to support a COVID related registry of patients with IBD
• We created a NOSI in April 2020 for applications exploring the relationships between rheumatic and musculoskeletal diseases and SARS-CoV-2. We committed $1.65M to 5 awarded projects in the Fall of 2020.
• Grantees were required to certify lab was able and ready to proceed before funds were released, though awards were still executed as normal.
• For some grant mechanisms we added language noting that COVID-19 research relevant to cancer or persons living with cancer is welcome.
• new covid respiratory award
• We now have "covid research grants"
• We launched a grant called 'Open your data Drawers' to incentivize researchers to share unpublished research datasets.
• Small grant for Covid-19 study with regard to T1D; advocacy efforts toward having T1D prioritized for vaccination
• virtual support programs for patients
• Deploying funds to ensure and sustain programs locally where fundraising was negatively impacted; Telehealth
• expanded fellowship program
• Not to external research funding, but we added a section to our Natural History Database to collect information on people diagnosed with COVID-19.
• Zoom Review for our Fellowship and Lloyd J Old STAR Programs
• As part of programs, funds have been prioritized for grants that focus on COVID-19 related questions.
• Wire transfers for all award payments, all electronic documents and signatures.

Q 32. Has your organization allowed grant funds to be used in new ways during COVID-19?

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<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
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<tbody>
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</tr>
<tr>
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<td>6</td>
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<tr>
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<td>0</td>
</tr>
<tr>
<td>No Response</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

Q 33. If yes, please describe.
• In some cases grantees have reallocated travel funds to add some additional research related to COVID-19.
• Our funding is already flexible so if individuals wanted to pivot work towards a COVID focus they were able to do so without coming to us for approval/grant amendment.
• Very flexible in terms of granting requests for funding reallocation and no cost extensions
• Shift more towards salary support
• 10k allowance for COVID related expenses (awardee was required to provide justification for expense)
• Our organization has allowed grant funds to be used in new ways during COVID-19 but only on a limited basis. Supplemental funding was offered to active grantees with the purpose of filling budgetary gaps resulting from the research slow down or shut downs. A small number of grantees had the opportunity to add COVID-19 related work so we allowed using of a small part of the grant toward that purpose.
• Some PIs asked to use existing grants to work on COVID-19 related research.
• General operating support for clinics and COVID research
• Travel funds may be used for virtual meetings and remote professional development
• Not necessarily but we have been more flexible with rebudgeting and changing specific aims
• Some flexibility for minor changes in research activities
• We have been very flexible about re-budget requests.
• Can be used for childcare. Can be used to replace funds lost through institutional bullshit.
• Our Care Centers were allowed to use their grants to support Telemedicine programs
• Convert travel funds to other uses.
• 1) Financial support for lung cancer patients during the pandemic  2) Education related to COVID-19 (webinars, print, website)
• We have revisiting work plans with grantees and allowed for changes due to COVID-19.
• support for virtual training/workshops

Q 34. Did your organization change the percentage of funds allocated to research as a result of COVID-19?

<table>
<thead>
<tr>
<th></th>
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<tr>
<td>Yes – decreased</td>
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</tr>
<tr>
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<td>0</td>
</tr>
<tr>
<td>No Response</td>
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<td>4</td>
<td>4</td>
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</tbody>
</table>

Q 35. If yes, please describe.

• Due to decline in endowment as a result of Covid-19, 2021 budget amounts were allocated differently to other portfolio areas, with research budget being decreased the most, as other program areas support projects that have more direct impact on individuals (families/children, artists)
• At first, budget was decreased. As the stock market recovered, each program is allowed normal pre-pandemic number of grant allocations.
• We reduced our planned spend for research awards.
• We committed funds to 5 additional projects that were related to COVID19.
• We halted most new awards over the past year.
• Temporarily decreased percentage of funds for grants until fundraising activity recovers
• I mean, we had zero funds allocated in 2019 and found some in 2020 so I guess that’s where the answer came from.
• Reduced the dollar amount on research grants
• Even if we did not change the percentage of funds allocated, we ended up spending less money on grants. This was because we received fewer applications and proposals. Some labs were not able to submit proposals, all of them required a longer timeline to activate their grants.
• When the markets fell, we were conservative and cut some grant funding to ensure the endowments did not go in the red.
• Decreased grant funding by 2/3; % of total org expense allocated to mission also decreased
• we decided to be conservative and award less money
• Deployed funds allocated for new grants to be used to sustain local support programs and services.
• Research grants awarded decreased by about 40% and we did not offer one of our grant programs at all.
Q 36. Has your organization changed the type of grants/awards offered as a result of COVID-19?

<table>
<thead>
<tr>
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<th>Endowment</th>
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<tr>
<td>No Response</td>
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</table>

Q 37. If yes, please describe.

- Prioritizing early career and trainee support as well as diversity supplements to current awardees.
- In 2021 we were not able to offer all of the grant opportunities we typically offer. We expect to return to our usual offerings within 1-2 years.
- Added a new award for covid.
- We continue to offer "covid research grants".
- We included a new grant type called 'open your data drawer' that provided $10K for data-sharing of existing research datasets.
- This year we were unable to offer Innovative, new training, and project concepts as openly available opportunities. We also suspended conference support.
- Decreased categories of awards and added some RFA-driven awards supported by specific donors.
- We did not open all grant categories due to decreased funds available to grant. We hope to open them again in the coming year.
- Did not offer one of our grant programs in 2020 due to insufficient fund raising to support it.
- In other program areas yes (emergency funding to arts organizations, artists, families), but not so much in research portfolio other than some additional unrestricted funds for current grantees.
- Organizational changes: implemented DocuSign for all award terms to help with collection of signatures in a remote work environment; invited some small discussion groups for our awardees to tell us about their challenges and how we can help. Award terms changes: Automatic one-year grant extensions for all awardees; allowed the reprogramming of travel funds to be spent on child or elder care costs; extended eligibility timelines for our postdoc and young investigator awards.
- Allowed for modification of research designs as were required due to changes in research settings and extended deadlines.
- We offered supplemental funding, I am not sure that is a change in the types of grants. It is in the sense that we do not typically offer supplements.
Q 38. Has your organization made changes to its research programming as a result of COVID-19? Select all that apply.

<table>
<thead>
<tr>
<th>Yes - we had to cut programming</th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes - we added COVID-19 related programming</td>
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<td>3</td>
</tr>
<tr>
<td>Yes - other</td>
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<td>2</td>
<td>1</td>
</tr>
<tr>
<td>No - we have not made notable changes to our programming</td>
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<tr>
<td>Don't know</td>
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</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
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</tbody>
</table>

Q 39. If yes, please describe any other programming changes your organization made as a result of COVID-19.

- We had to move to virtual grantee and scientific meetings
- Our programming focused on predoc, postdoc, and early career investigators. We limited opportunities specifically for established investigators. We also funded a round of COVID rapid response projects (22) in addition to a coordinating center.
- We formed a COVID-19 Task Force to provide guidance statements to our community
- We skipped one grant cycle for most of our standing award programs
- We created virtual engagement opportunities including a virtual Call for Applications and a Summer Research Series.
- We made our annual researcher summit virtual.
- We were not able to offer all of the grant mechanisms that we typically offer in a given year, including our own travel grants and travel awards we provide collaboratively with other organizations, providing funding to a Cold Spring Harbor Course, and our Research Alumni meeting was moved to a virtual platform for 2020 and 2021. We expect that all of these changes will be temporary.
- We cut our Health Professional Training Program, which included oncology social work, oncology nursing, and cancer prevention training for primary care physicians.
- We reduced the number of grant programs offered and added a lot of community information and resources on COVID and allowed Care Centers to use funds for Telemedicine
- our annual national conference went virtual we created Zoom support groups and subsequently expanded them
- Lack of in-person conferences and workshops
- We had to cancel one annual grant program due to fundraising shortfalls.
- We added up to 6 months of extension funding to some of our existing awards.
- We’ve cut an in-person research retreat; we may opt for virtual or push to 2022
- AES PRO offered (Professor's Round Online); hosted our annual Fellows program virtually
• Paused a grant mechanism (collaborative research grant) for now - dk yet if/when will be reinstated and cancelled a funding cycle of other grant mechanism.
• We had planned on having a booth at AcademyHealth’s Annual Research Meeting to get input on research-health system partnerships but the in-person meeting was cancelled.
• In-person meetings were cancelled but reformatted to online format. This limited programming for networking. So, programming was not cut but rather curtailed by the circumstances and the limitations of an online format.
• We made all programs virtual, but didn’t cancel any programs.

**Q 40. If programming was cut, how did your organization determine which programming to cut?**

- Focused on career stage. Convened an expert panel of volunteers and they recommended a focus on trainees and early career investigators.
- We cut some of our in-person medical education programs that rely on partnering with in-person events.
- Programming related to travel and meetings were cut first due to travel restrictions. Other cuts that were made were only to grants and programming for which we did not yet have a contract in place. Our budget for new grants were cut in 2020 and then, for 2021, we cut new offerings for our largest grants.
- Internal working committee.
- Most of the cutting was determined by the fact that most research institutions were not able to participate in or create new research programs.
- We cut across the board.
- Grant programs were prioritized based on an entirely new strategic plan, and significant staff decrease.
- We consulted our research advisory committee about how to prioritize very limited funds and were told to focus on training fellows.
- Pandemic conditions—travel and social distancing.
- Yes, in consultation with our scientific advisory committee, we decide to cut the translational grant program.
- We postponed payments on a grant for a clinical trial that would not need it due to pandemic-associated delays, and we delayed a special funding program for newborn screening for a year. We did not eliminate any already-awarded grants and we awarded our regular number of new grants.
- One program was suspended to allocate resources to community health efforts related to COVID-19.
- Prioritized offering additional funding to current grantees over funding new research grants.
- Rather than cut programming, we compressed our annual meeting into less hours based on our experience about how taxing it can be to spend long hours on Zoom.
Q 41. Has your organization's staffing been impacted by COVID-19? (Please select all that apply)

<table>
<thead>
<tr>
<th>Has your staffing been impacted by COVID-19?</th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowments</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>No - Our staffing has not changed due to COVID-19</td>
<td>12</td>
<td>4</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td>Yes - We had furloughs, hiring freezes, or partial reductions in hours due to COVID-19</td>
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<td>0</td>
<td>0</td>
<td>12</td>
</tr>
<tr>
<td>Yes - We eliminated staff positions due to COVID-19</td>
<td>10</td>
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<td>1</td>
<td>11</td>
</tr>
<tr>
<td>Yes - Our staffing was negatively impacted in other ways</td>
<td>2</td>
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<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Yes – Our organization’s staffing increased</td>
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<td>1</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Don't know</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Q 42. If yes, please describe.

- We had furloughs, hiring freezes, or partial reductions in hours due to COVID-19 and we eliminated some staff positions.
- We reduced staffing across all departments
- Several staff were furloughed, some were brought back and others were laid off.
- We had hiring freezes on all open positions that were posted before the pandemic or that opened up during the pandemic. Staff accepted salary reductions, with no change in total hours, and the 401K match was cut for all staff for the last 4 months of 2020 and into 2021. We do not yet know when the cuts will end, but have been promised back pay for the lost salary when full salaries are reinstated.
- We laid off about 1,000 staff
- Layoffs - no raises and furloughs
- N/A we are small and were lucky not to have to furlough anyone.
- Very modest staff reductions.
- We furloughed two staff for a short period. Hiring freeze for the year. We did not replace one position when the staff member left.
- 46% of staff laid off after two month furlough; 20% temporary pay cuts across the board
- We furloughed over 50% of our organization and then eliminated many positions permanently. Our staff has effectively decreased by 50%
- Hiring freeze
- 9 month hiring freeze was imposed, slowing down our planned growth
- We had hiring freezes but were able to retain all existing staff.
- We eliminated two administrative positions because the physical office was closed for several months.
- We had to hire to sustain virtual activities
- We were planning to hire two new people before the pandemic. Those budgets were already written and we proceeded with the hires.
• No staff cuts. Hired two new staff members, with plans to hire more in the coming fiscal year.
• ASCO created a COVID-19 Registry to help the cancer community learn more about the patterns of symptoms and severity of COVID-19 among patients with cancer, as well as how COVID-19 is impacting the delivery of cancer care and patient outcomes. The ASCO Registry is designed to collect both baseline and follow-up data on how the virus impacts cancer care and cancer patient outcomes during the COVID-19 pandemic and into 2021
• We eliminated an office administrator (front desk) position.
• Our core staff did not change beyond voluntary retirements or moves. However, we made more use of part-time contractors to manage increased workloads.

Q 43. Did your organization undergo a reorganization (E.g. shutting down or selling divisions, replacing management, cutting budgets, and laying off workers) as a result of COVID-19?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes - We went through/are going through a reorganization</td>
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</tr>
<tr>
<td>No - This has been discussed, but we have decided not to</td>
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</tr>
<tr>
<td>No - This was never discussed</td>
<td>11</td>
<td>6</td>
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<td>0</td>
</tr>
<tr>
<td>No Response</td>
<td>8</td>
<td>3</td>
</tr>
</tbody>
</table>

Q 44. If yes, please describe.
• Collapsed and merged some divisions. Reduction in force and reorganization.
• We laid off workers
• Some organizational changes, but probably would have happened even w/o COVID
• We did lay off a few staff and we reduced budgets to the extent possible.
• We laid off about 1,000 staff and have narrowed our focus to maximize impact in strategic areas.
• I don’t consider this a reorg. We cut our budget and all staff were asked to look at ways to save money. We happened to be in talks with APTA to become and affiliate pre-COVID. This does change our structure somewhat but it’s unrelated to COVID.
• Cut budgets across the board.
• Research strategy was refined and streamlined such that staffing reductions corresponded. Chapters were consolidated such that nearly half of nationwide chapter offices closed.
• All areas of the organization have reorganized multiple times in the last year to accommodate staffing furloughs, eliminated positions and some attrition among staff who were competitive for other jobs
• Program budgets were cut but not any staffing. Annual COLAs were not given to employees.
• Certain positions, such as office reception were not needed in 2020, but we decided to rework job descriptions temporarily to keep everyone employed.
Q 45. Did your organization undergo a restructuring (e.g., a change in the structure or ownership through a merger or consolidation, spinoff acquisition, transfer, recapitalization, a change in name, or a change in management) as a result of COVID-19?

<table>
<thead>
<tr>
<th>Response</th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes - We went through/are going through a restructuring</td>
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<tr>
<td>No - This has been discussed, but we have decided not to</td>
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<tr>
<td>No Response</td>
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<td>3</td>
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</tbody>
</table>

Q 46. If yes, please describe.
- We changed CEOs

Q 47. How has teleworking and remote work among your staff changed? (Note: teleworking refers to staff who live near an office and had/have the option to be physically present on-site. Remote work refers to staff who do not live near an office.)

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>December 2020 - What percentage of your employees were remote workers?</th>
<th>December 2020 - What percentage of your employees were teleworking at least some of the time?</th>
<th>December 2019 - What percentage of your employees were remote workers?</th>
<th>December 2019 - What percentage of your employees were teleworking at least some of the time?</th>
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<tbody>
<tr>
<td>91-100%</td>
<td>17</td>
<td>19</td>
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<td>81-90%</td>
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<td>71-80%</td>
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<td>31-40%</td>
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<td>21-30%</td>
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<td>11-20%</td>
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<tr>
<td>&lt;10%</td>
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<td>1</td>
<td>11</td>
<td>5</td>
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### Societies

<table>
<thead>
<tr>
<th>91-100%</th>
<th>December 2020 - What percentage of your employees were remote workers?</th>
<th>December 2020 - What percentage of your employees were teleworking at least some of the time?</th>
<th>December 2019 - What percentage of your employees were remote workers?</th>
<th>December 2019 - What percentage of your employees were teleworking at least some of the time?</th>
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<td>&lt;10%</td>
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### Endowments

<table>
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<tr>
<th>91-100%</th>
<th>December 2020 - What percentage of your employees were remote workers?</th>
<th>December 2020 - What percentage of your employees were teleworking at least some of the time?</th>
<th>December 2019 - What percentage of your employees were remote workers?</th>
<th>December 2019 - What percentage of your employees were teleworking at least some of the time?</th>
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<td>0</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>&lt;10%</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
December 2020 - On average, how many days per week did teleworking employees telecommute (work from home)?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>4.65</td>
<td>4.60</td>
<td>4.50</td>
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</table>

December 2019 - On average, how many days per week did teleworking employees telecommute (work from home)?

<table>
<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td>1.62</td>
<td>1.50</td>
<td>1.40</td>
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</tbody>
</table>

Q 48. To what extent do you agree with the following statements about remote work / telework?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Remote work / telework has had almost no impact on organizational performance.</th>
<th>Remote work / telework has had almost no detrimental impact on individual performance.</th>
<th>Remote work / telework has presented almost no challenges.</th>
<th>My organization has a clear remote work / telework strategy.</th>
<th>Remote work / telework has not changed our organizational culture.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely Disagree</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Disagree</td>
<td>4</td>
<td>2</td>
<td>8</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Neither Agree nor Disagree</td>
<td>3</td>
<td>4</td>
<td>5</td>
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</tr>
<tr>
<td>Agree</td>
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<td>9</td>
<td>13</td>
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<td>9</td>
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<tr>
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<td>12</td>
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<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Don’t know / Prefer not to answer</td>
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<td>1</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>No Response</td>
<td>6</td>
<td>6</td>
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<tr>
<td>Societies</td>
<td>Remote work / telework has had almost no impact on organizational performance.</td>
<td>Remote work / telework has had almost no detrimental impact on individual performance.</td>
<td>Remote work / telework has presented almost no challenges.</td>
<td>My organization has a clear remote work / telework strategy.</td>
<td>Remote work / telework has not changed our organizational culture.</td>
</tr>
<tr>
<td>-----------</td>
<td>---------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
<td>-------------------------------------------------</td>
</tr>
<tr>
<td>Completely Disagree</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Disagree</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Neither Agree nor Disagree</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Agree</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>2</td>
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<tr>
<td>Don’t know / Prefer not to answer</td>
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<tr>
<td>No Response</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
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</table>

<table>
<thead>
<tr>
<th>Endowments</th>
<th>Remote work / telework has had almost no impact on organizational performance.</th>
<th>Remote work / telework has had almost no detrimental impact on individual performance.</th>
<th>Remote work / telework has presented almost no challenges.</th>
<th>My organization has a clear remote work / telework strategy.</th>
<th>Remote work / telework has not changed our organizational culture.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Completely Disagree</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Disagree</td>
<td>2</td>
<td>3</td>
<td>6</td>
<td>6</td>
<td>5</td>
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<tr>
<td>Neither Agree nor Disagree</td>
<td>2</td>
<td>2</td>
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<tr>
<td>Agree</td>
<td>5</td>
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<tr>
<td>Strongly Agree</td>
<td>5</td>
<td>5</td>
<td>1</td>
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<td>1</td>
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<tr>
<td>Don’t know / Prefer not to answer</td>
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<td>1</td>
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</tr>
<tr>
<td>No Response</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
Q 49. Please describe the impact of COVID-19 on your organization's approach to remote work and teleworking.

- We learned that we continue to be able to work efficiently and will move to a hybrid model once the pandemic ends.
- Not being able to attend scientific conferences and hold events reduces networking opportunities and organizational visibility.
- IT has made us re-evaluate our telecommuting policy, and are in the process of having a more formal policy spelling out expectations and conditions for telework.
- Organization is office based but had many teleworkers before, the pandemic accelerated that trend.
- In the past we provided flexibility to staff to WFH on a limited basis. The challenge was converting to all remote with short notice, just after an office move. We have a small staff (5) so we have been fortunate to be able to make the adjustments needed to be productive as a remote team.
- Our office has been very responsive to the needs of the employees during this time. I believe that it has opened the eyes of leadership to re-vision what the office could/should look like in the future and allow individuals to choose the work environment (at office, hybrid, telework/remote) that works best for them and their role.
- Before COVID, we had very few remote employees and teleworking was not part of company ethos. Moving forward, I suspect it will be.
- The covid 19 pandemic showed leadership working from home can work.
- We meet twice a week. It's been tough. Some of us are working as hard and making it work, others just are using it as an excuse not to be available when they should be.
- We transitioned to 100% remote work in mid-March 2020 and do not plan to return to the office before Sept 2021. Mostly likely return to the office will be a gradual/hybrid re-entry.
- Our organization's approach to remote work did not change much: we were already on a policy of up to 3-days/week teleworking for all employees, with COVID-19 we then institute a fully remote working policy. Covid has leveled the plainfield for remote and the NYC staff closer together. Before: people on screen and people together - during covid: everybody on screen.
- Our employees were required to work remotely throughout 2020. We have now adopted the policy that workers can choose remote or in-person work in the office.
- I think it has shown board members and senior staff that employees can be just as effective working remotely.
- Staff was already prepared to telework. We made changes to billing/payments.
- 100% of staff has been working remotely 100% of the time. We've been technologically well-equipped and staff has been extremely, if not more so, productive. Culture and job satisfaction has suffered, largely due to burnout due to staff decreases.
- Our organization has been 100% remote since the pandemic started and we have eliminated the field offices in all 50 states, likely permanently. We may only maintain a split headquarters in Chicago and New York.
- As a result of the pandemic, we have fully embrace a "work from anywhere" approach. Even after the pandemic, we anticipate that most staff will NOT return to the office full time. Furthermore, for new positions we plan to hire from anywhere-- not just locally.
• On an emergent basis and ongoing throughout the year, last March we pivoted to 100% telework. We do not yet know our policy re: telework going forward (post pandemic); we have begun to post some jobs as potentially remote.

• The impact of Covid19 varied on a departmental basis. On the grants team, we have our files in the cloud already and so just relied less on printed materials. Other departments, like event planning and fundraising were more drastically affected because their work had relied on in-person contact which as disrupted.

• We know we can make it work for most responsibilities and tasks, but we also see the value of in-person office to the culture. We will likely be more flexible with telework after the pandemic is resolved, but that is yet to be determined.

• Found remote/teleworking to be successful and expect to continue beyond COVID

• Our leadership was very positive about remote work. We even had a Wednesday-meeting free policy to help staff who had childcare and other caregiving needs.

• Our organization had always had remote employees within the larger org, our group had been minimally impacted in terms of having access to files, personnel, technology, due to the ability to work from home. The largest organizational approach that was conveyed was to ensure that employees are still able to step away from work while working from home so as to help maintain work-life balance. Our organization has also provided supplemental funds for employees to purchase home office supplies to help make working from home more comfortable. Conveying that it is okay for people to work more flexible hours to account for child care, and normalizing children sometimes being present during meetings.

• We see that we can be flexible and will consider options besides fully in person in the future.

• COVID19 forced those local to telework more from Mar2020-Dec2020, but because we had remote employees before it was not a difficult transition

• We always permitted telework and flex scheduling, so in that respect no change and has reinforced the value of allowing that flexibility. We need to consider more intentionally how we maintain organizational culture and also help employees find better work/personal balance.

• We were not prepared for remote/telework but staff worked quickly to get ready to dive in which was successful. It took time to develop best practices for it and to get into a rhythm as a team but overall it has been successful.

• Pre-COVID, the organization was very anti-telework and anti-remote work. Now that they have seen how our work can be done using telework they are putting a policy in place for the future. The details haven't been released yet.

• Prior to Covid the only people who worked remotely on occasion (often due to travel but not always) were program staff, and other departments did not allow their staff the flexibility to do so. Now everyone works remotely, with no current plan to reopen the office yet, and I believe there will be more flexibility for remote work for all employees.

• We had challenges onboarding new staff, but otherwise no problems migrating to remote.

• This is the first time our organization has ever offered remote work. We had to create several new policies and practices to carryout essential tasks we would normally manage
in person (e.g., signing checks, processing payments, etc.). We also had to establish new ways to communicate in a virtual environment (e.g., using zoom and Microsoft Teams).

- Remote work became acceptable whereas pre-pandemic, it was strongly discouraged.
- It will likely make teleworking much more prevalent, long term.
- As of March 13, 2020 our employees moved to remote work. Since July 2020 the office has been open at 50% capacity and uses contact tracing. Once conditions allow, the foundation will provide a 30 day notice period at the end of which all staff will resume working from the offices.
- Telework was required for 3 weeks and then was encouraged, although we have been able to work in the office. With a small office and virtually the only ones in the building at present, we have not had an issue with using the office. Major issue has been being able to get technical support when needed. During full closure of office, we were not able to access files remotely so had to download necessary files to flashdrives which was cumbersome.

<table>
<thead>
<tr>
<th>Q 50. Did your organization reduce its footprint in 2020?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fundraising</strong></td>
</tr>
<tr>
<td>Yes - We sold office space and/or land that we own</td>
</tr>
<tr>
<td>Yes - We reduced the amount of office space that we lease</td>
</tr>
<tr>
<td>No - We did not, and have no plans to reduce our footprint</td>
</tr>
<tr>
<td>No - We did not reduce our footprint in 2020, but are currently discussing this</td>
</tr>
<tr>
<td>No - We increased our office space (via either purchase or lease)</td>
</tr>
<tr>
<td>Don't know</td>
</tr>
<tr>
<td>Prefer not to answer</td>
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</table>

<table>
<thead>
<tr>
<th>Q 51. Did your organization introduce any other voluntary cost-cutting measures in 2020?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fundraising</strong></td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Don’t Know</td>
</tr>
<tr>
<td>No Response</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q 52. If yes, please describe your organization's voluntary cost-cutting measures.</th>
</tr>
</thead>
<tbody>
<tr>
<td>• No travel, no face-to-face meetings, no catering, no overtime, no contractors</td>
</tr>
<tr>
<td>• We reduced each of our grant awards by 10%</td>
</tr>
<tr>
<td>• Many changes to reduce operating expenses across the board</td>
</tr>
<tr>
<td>• All in person meetings transitioned to virtual and there has been no staff or volunteer travel.</td>
</tr>
</tbody>
</table>
no travel
We implemented a salary/hiring freeze, senior staff salaries were reduced, and we curtailed planned investment relating to our strategic plan.
We cut across the board in each department.
Furloughs, temporary pay decrease, layoffs, grant reductions, budget reductions, travel suspended, operating cost reductions, chapter offices closed
Our Executive staff voluntarily reduced pay for four months and some extended beyond that time
Salary freezes, no travel.
awarded one less pilot grant
The top 20% most highly compensated employees took a 10% pay cut with an opportunity to have it paid back based on year-end financials. It was paid back.
No staff travel
Postponed marketing strategy to following fiscal year, virtual events and virtual award selection meetings. Executive salaries frozen for 2020.
Primarily no travel, which was not really voluntary. We did not make any other significant cost reductions other than those that were a direct result of COVID limitations
Based on a review of needs of the organization going remote for an extended period of time, we decided to close and open position that had not been filled.

Q 53. Please describe any involuntary changes that resulted in cost-savings in 2020.

We saved a significant amount in office expenses (paper, toner, coffee, staff travel etc.)
We were not able to plan live events or hold live conferences
travel and in person meetings and conferences were reduced or eliminated
Due to the lack of in-person events we did not spend as much exhibiting or on our med education programs
We had voluntary staff turnover in Q4 that reduced payroll costs but increased some professional services.
Travel, in-person event cost (we managed to get lift-and-shift agreements with most event spaces)
Many staff were moved to four days a week for several months to conserve cash
no travel
With no travel allowed, there were savings there. Also expenses related to in person events were also not realized so some savings there as well.
Layoff of 10% of staff.
Some admin fees for planning events were reduced because of no-in-person events; also, cost-savings from not attending conferences in-person occurred.
See above- COVID restrictions mandated certain changes, but we did not make any cuts to programming or staff benefits.
The lack of in person meetings and travel resulted in cost-savings in 2020.
Lack of travel and lack of events resulted in cost-savings.
No COLAs, program budgets reduced, certain open positions were not allowed to hire, not replacing staff who left.
Cancellation of meetings with flexibility of vendors to reimburse prior payments plus elimination of travel resulted in cost savings in 2020
• Lack of travel and meeting costs. In our transition to remote access to files, we also found some more cost effective vendors for communications services.

**Q 54. Are there any adaptations your organization made to its operations that you think were particularly beneficial?**

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<thead>
<tr>
<th></th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
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<td>6</td>
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</tr>
<tr>
<td>No Response</td>
<td>8</td>
<td>3</td>
<td>4</td>
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</table>

**Q 55. If yes, please describe the adaptations.**

- working remotely
- Flexibility with remote work, quick adaption to Zoom, deep dive into Teams, accelerated a lot of the tools we now use daily.
- better efforts to include everyone, including remote workers, in meetings; better use of software tools
- We streamlined some processes for donation acknowledgements and reporting. We would have done this anyway but addressed these sooner with the conversion to remote working.
- Improved efficiencies in HR and ops
- Remote work pushed computer and other technological upgrades (Zoom subscription for example).
- Using Slack for engagement/communications with staff, switching to a VOIP phone, using zoom for meetings/conference calls, holding online events (had pros and cons)
- working remotely
- I think opening up some of our fundraising events to online and allowing a wider range of participants rather than just local to NYC has been beneficial
- Salary/hiring freeze, curtailed investment in strategic plan initiatives
- Flexibility in work schedules. All staff fully equipped with technologies to successfully work from home. New lease to coworking space, moved to a lockbox to collect donations, changed our permanent address to a UPS PO box.
- Use of Zoom and virtual platforms for virtual events. We will likely continue to use a hybrid approach of a mix of in-person events and virtual moving forward. We felt this promoted more inclusivity with international partners who were not able to travel in the past.
- Holding virtual events with content researcher want has been well received and our most highly attended events. Our virtual events in general have expanded our reach. Our board now sees they can have effective meetings in a virtual environment.
- only really beneficial thing will be increased availability of remote work structure and events that supporters can join from anywhere
- Our virtual capabilities (meetings, conferences) increased exponentially and will continued to be used even when things open up. Also Care Centers will continue to use Telemedicine
- embracing work from anywhere and flexible hours as a permanent part of our workplace
- Use of video meetings
- Amped up cybersecurity; implemented weekly staff virtual coffee breaks to maintain team connection. Pivoted support groups to web- and phone-based. Pivoted awareness and fundraising events to virtual.
- Zoom has completely replaced telephone conference calls, which is better for engagement and has saved hundreds if not thousands of dollars. We are now much more comfortable with technology which will improve our interactions with permanently remote workers compared to pre-pandemic times.
- allowing remote work. I think it helps with staff morale and talent outreach. I was a big proponent of remote work prior COVID19
- Teleworking
- Reducing office space given the high percentage of staff already telecommuting before the pandemic
- Ensuring that teams could work remotely effectively was beneficial to the organization.
- ACH payments DocuSign capabilities across the organization
- Providing some flexible funds for employees to use towards home office purchases was beneficial. Conveying that it is okay for people to work more flexible hours to account for child care, and normalizing children sometimes being present during meetings.
- Virtual award selection meetings. Adoption of electronic banking for all transactions. Use of Zoom for Board/Board committee meetings instead of phone or in person.
- Quarterly need based payments to grantees
- Good lessons from going to virtual format for our annual meeting- some aspects we will continue, such as more robust online platforms for education and networking. Some activities may remain virtual.
- We moved to full remote/telecommuting work environment, Some other adaptations include the institution of core hours and flexibility for staff outside of those core hours to allow for all different telework situations. Another adaptation was the institution of more regular check in and staff meetings in order to keep a connection among employees. The organization also provided staff with a small stipend to help to set up their home offices better and provided easy ways to order needed supplies for their home workspace.
- Moving payments to ACH; setting up everyone's IT to support remote work
- Implementing DocuSign for signatures and payment confirmations was easy and has really improved our tracking and collection of these documents.
- The organization had IT take an active role in making sure that everyone had what they needed to make work from home successful
- Flexibility to work remotely from anywhere, and providing some resources needed to do it effectively such as monitors, headphones, web-enabled phone system, etc.
- We made conferences virtual and saved money by doing this. In the future some conferences will be virtual by default.
Q 56. Will any of these adaptations continue beyond the pandemic?

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<thead>
<tr>
<th>Response</th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, we are making / have made permanent changes to our policies</td>
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<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Yes, for the foreseeable future</td>
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<tr>
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<td>No Response</td>
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</table>

Q 57. Overall, how has COVID-19 impacted your organization?

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<tr>
<th>Impact</th>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
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<tbody>
<tr>
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</tr>
<tr>
<td>Negatively</td>
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<td>2</td>
<td>5</td>
</tr>
<tr>
<td>No Impact</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Positively</td>
<td>7</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Very positively</td>
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<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Prefer not to answer</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>No Response</td>
<td>9</td>
<td>3</td>
<td>5</td>
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Q 58. Please summarize the overall impact COVID-19 had on your organization.

- While there were changes as a result of working at home, and we had to make some adaptations, this had no impact on the ability to fully function and implement our programs.
- Despite the hardships of teleworking etc... we have fared well during the pandemic. We have increased our funding amount and the number of projects we fund. We are fortunate and proud of all BrightFocus' departments and employees. We have all pulled together and worked hard to keep the wheels turning and couldn't be more happy with the outcome.
- Overall, I think working remotely let our organization reset on some negative morale
- If I had the option above I would say "both positive and negative." Some positive impact on efficiency and culture, negative impact on fundraising and staff stress levels.
- While we have maintained our fundraising base and productivity, my concern is for the long-term culture of the organization. It has been a challenge to onboard new staff members when we cannot build relationships in person. Everyone has had to balance work and family to a greater degree than ever before and that takes its toll despite efforts to bring the team together, build in touchpoints, and provide flexibility for staff.
- It forced us to innovate in a big way. We have reimagined how we engage with awardees, donors and other stakeholders. It has also forced staff to be more intentional about information sharing and communications.
- COVID negatively impacted our ability to fundraise to the same extent, but I think COVID positively impacted the way we think about work, from sitting in an office 8-5 to a more flexible model.
- Devastating negative impact on our peer to peer, walks/runs, fundraising events
- The large-scale layoffs have been a significant challenge.
• It has allowed us to reprioritize our activities to think about what is really essential. We are asking more of our employees - they work flexibly - and we understand child care is an issue - but if they are not around during the day they need to do stuff at another time. We are 4 women all with children so I think we inspire each other to get stuff done.

• Overall, we are unable to fund research at the same level. The impact of this is felt on individual labs who have had to cut staff. We had lost valuable talent who sought better opportunities in less vulnerable industries.

• COVID-19 had a global impact across all departments of our organizations. From fundraising and maintaining our relationship with our community to changing all our in-person events to virtual, to the substantially increased internal programming that required a lot more zoom meetings creating fatigue with extended extra hours required to conduct our activities.

• It was a difficult year for employees who had to shift their home-work life balance. The reduced capacity of researchers with university mandated lockdowns and reduced fundraising were difficult, but overall we fared quite well as an organization. We did not have to cut staff or resources and are on track to maintain our previous levels of support for research. The shift to a hybrid work plan has been positive for our work culture.

• The loss of funding and having to cut grants and scholarships set us back but we are positioned to grow.

• COVID-19 has moved all staff to almost 100% remote work. Fundraising suffered and we decreased services and research grants.

• as described above

• Dramatically reduced size and capabilities of the organization.

• It has impacted our fundraising, which is disappointing, though not nearly as much as we had initially feared it would!

• Reduced funding to support critical mission goals and objectives.

• Negative, especially since the process of building and maintaining a sense of connection and community among those affected by this disease is central to our mission.

• We were unable to fundraise as much as we needed to maintain or exceed the previous year's grant awards. We were able to avoid cutting staff. We became more adept at using remote tools and working in the cloud. Moved away from traditional paper methods. We relied on the existing working relationships that were forged pre-pandemic but most people missed their colleagues and look forward to some in person time. Others found a new work-life balance without a commute that they will be reluctant to give up.

• The decrease in fundraising coupled with the time sink of having to plan for multiple unknowns and contingencies in 2020 has set us back at least a year in many ways. We will recover and thrive, but we would have been further ahead without the pandemic.

• Of course, it has impacted everyone negatively BUT, for this survey, I can objectively say that it has impacted us positively. It was a stress test that we had to utilize to continue our mission and we are more efficient to a certain extent. Our patient population is very isolated due to the disease, and COVID19 forced us to deploy way to sustain support groups remotely. This has created great value for our patients. Our staff is pleased to be able to work remotely and it wasn’t a choice before. So people have been able to move in more affordable zip codes. we’ve been able to develop communication streams with our donors, supporters, and the caregivers and patients we help more efficiently.

• - Minimal overall impact
• It has made us more nimble and flexible, and honestly has probably brought the staff members together.
• I believe that COVID-19 has allowed our organization to accommodate more flexible work conditions to help enable people to maintain balance between life and work. Furthermore, it has highlighted the need for further support for employees in navigating particular challenges, and as such, has set up support groups to discuss challenges.
• Burn out with video meetings and blurred work/home life boundaries
• Cost savings from not attending conferences  Cost savings from not hosting a research retreat  Adjustments to research deadlines and no-cost extensions for research projects given.
• By no impact, we mean a balance of the positive and the negative that overall has been relatively neutral in the short term- some uncertainties may have longer term impacts we can't predict.
• The Foundation moved from an in person work environment to a fully remote work environment. While there was the option for occasional telecommuting, it was not the norm but how well we have responded may change that for the future. We have had many grantees who have not been able to complete their work (due to in person data collection suspended; no travel; hiring freezes; etc.) and they have requested extensions and supplements to try to compensate for lost time and effort on the project. We have tried to provide as much as support and flexibility as we can while remaining faithful to our Charter. We expected more of a negative impact to our endowment but were pleasantly surprised that it was not the case so we did not have to reduce our grantmaking or internal budgets.
• We have been fortunate to continue our funding programs and keep staff during this time. From a programmatic standpoint, it has been okay. From a staff perspective, individuals are struggling to manage workloads and teams remotely as we weren't prepared to do this. Operationally, we are struggling to decide what to do with a large amount of office space as a remote telework policy will go into effect at some point.
• More attention to culture; hopefully more employees will have flexibility to work remotely; IT infrastructure to work remotely for everyone.
• In the context of our medical research grantmaking, we have had to address special circumstances and challenges with individual grantees much more than usual. Other than that, we are able to function remotely in a similar manner to pre-pandemic.
• Both positive and negative aspects  Positive: culture shift in WFH attitudes  Negative: lots of communication issues compounded by virtual setting
• Our endowment increased during the pandemic and our Board approved spending beyond our typical plan amounts to support COVID-19-related initiatives.
• While being thrust from a collaborative work environment to a more isolated one was a negative impact, the resilience that employees have shown and the ability to accommodate remote work in a very full way have both proven to be positive impacts that will live on beyond the pandemic.
• Even though remote work has had almost no detrimental impact on the organization's performance, team members dearly miss the social aspect and interactions that would take place when coming into the office.
• The impact has been positive in some ways (forced constructive innovation) and detrimental in others (culture, trauma stress of the pandemic has definitely taken a toll)
• Would not call it positive or negative although we are learning to do more online and with new communication tools.

Q 59. What has been your organization's biggest challenge during COVID-19?

• Fortunately there were no significant challenges.
• No social events or conferences
• Trying to pivot quickly on processes and re-allocation of funding that is responsive to the current needs of the community.
• Impact of pandemic on research sites
• Communications and culture. Supporting and preserving both.
• Planning our annual Scientific Retreat
• Inability to host events for fundraising and the uncertainty around how much we will raise and the impact that will have on our grant programs.
• Fundraising – see above
• fundraising
• fundraising and not being able to meet in person
• Fundraising
• Fund raising
• Fundraising
• Fundraising.
• Grassroot fundraising
• Event fundraising  Cultural collaboration among staff
• Maintaining our staff life-work balance healthy and staff exhaustion - people worked extended hours and weekends; stress: very challenging to plan as there was a high climate of uncertainty; how to keep staff safe while managing donor/ volunteer expectations.
• The biggest challenge has been to provide support to our external stakeholders (families and patients affected by the disease and our large network of scientists) without an in-person events or meetings. The more personal connections that were made at our scientific symposium or fundraisers are really important for our community.
• The biggest challenge is that staff are overwhelmed doing more than ever. The pace is not sustainable and I am working to try to ensure people take time off and am looking for ways to streamline.
• Not having an endowment. Laying off half of staff, burnout on remaining staff. Less opportunity for advancing T1D research.
• Sustaining mission delivery
• Planning for a future with so many unknowns; maintaining connection with/among staff and community
• Pivoting away from in-person events for fundraising. Keeping the culture intact with remote and telework and fundraising.
• The unknowns of the pandemic's timeline and long-term impact. Also, trying to make strong progress and help our community while figuring out how to work effectively internally and planning for multiple contingencies.
• making sure our patient population was okay and continued to receive support.
- Moving all in-person events to virtual platforms especially when logistics had already been paid for.
- The biggest challenge has been to maintain contact with people virtually and ensuring that employees do not feel isolated. Additionally, while our organization has highlighted the need for work-life balance, the organization is dealing with the reality of the pandemic and the emergence of issues that have come to light that require more rapid responding.
- The uncertainty of the situation has made planning for the future very challenging, with respect to fundraising, marketing, award programs, staffing.
- Not being able to meet face to face with prospective grantees.
- Staying focused, moving forward with organizational initiatives was difficult
- We are a membership-based professional society. We put on an annual scientific conference each year. The switch to a virtual conference was the biggest challenge, and remains a challenge this year.
- Not able to have in person donor meetings in addition to not being in the office to have that in-person work experience
- Trying to provide grantees with support and resources while also adhering to our Foundation’s Charter.
- The transition to telework and managing staff morale during a very hard time.
- Adapting to all-online meetings; maintaining connects; knowing when to step back from end-to-end zoom meetings
- Budget cuts; figuring out how best to support grantee communities
- Addressing special issues of our grantees - their inability to recruit subjects, the delays in timelines due to labs not being accessible, etc. We have written lots of grant amendments, which increases our legal fees.
- The rapid pace of change that happened in 2020. We tend to plan for events and activities at least a few months in advance, but whatever plans you had in Feb had to be thrown out and redone for what we thought was a temporary shift, and then thrown out and redone again when it became clear that the changes would be more permanent and to respond to the social movements over the summer as well. So there was a lot of extra duplication/repetition of effort, but we are seeing some really positive changes that we will continue into the future as a result of the introspection that 2020 demanded.
- Balancing expectations with staff at various levels of family responsibilities
- Keeping pace with emergency needs during the pandemic
- working remotely constrains the creativity and spontaneity of idea development among staff and colleagues in other organization; also for staff members with at-home learning children there are WiFi and other complications
- Adjusting to fully remote work, and ensuring that ALL employees are included in the “workspace” when it is easy not to be seen
- Maintaining organizational culture
- Research and non research programming
- Remote access to files, technology support.
60. What is one piece of advice you would give to other funders of health research to help them mitigate the organizational impacts of COVID-19?

**Flexibility & Adaptability**
- Paperless/Electronic grant management system(s)
- Be realistic about changes required and make them sooner rather than later
- Adapt, be flexible, try new things - our virtual events turned out to be more successful than we originally thought they could be. Our productivity has increased, in my opinion, from working from home.
- Be as flexible as you are able, and keep your finger on the pulse of what your constituents are challenged by and try to respond.
- Be flexible and creative, and think carefully about how to support remote workers to maintain their enthusiasm and the culture of the org.
- Be flexible and listen to your staff and your grantees about what they need.
- Be flexible in your process and customize it - not everyone needed the same changes over time.
- be flexible; look for silver linings and embrace them as opportunities
- Empower the staff! Be flexible
- flexibility
- Maintain or increase past levels of support. Be flexible and creative, and think carefully about how to support remote workers to maintain their enthusiasm and the culture of the org.
- Have flexible leases. Try to share space when possible. Make sure everyone knows how to handle their own IT problems.

**Organizational Culture / Communication**
- Be intentional about org culture.
- Check in frequently with your staff members to see how they are doing personally.
- Clear, honest communication, even when it must be ambiguous
- Embrace change and communicate transparently & frequently
- have understanding senior leadership; only fund what you have readily available to pay
- Increase communication among team members and within your research community to better understand the challenges and address them as you can.
- The people of the organization are the most valuable asset. Taking care of the people that work for the organization has a direct impact on the quality of work and well-being of the organization.
- there is no one policy fits all for your staff. Be equitable in giving each person what you need
- Invest in infrastructure to support remote working. The majority of our people are thriving in this environment.

**Other**
- Focus on a few key priorities and ensure you can deliver on them; push everything else until later.
- Setting up, if you have not already, an operating reserve fund. We have 8 months of reserves, it was there if we needed it.
- Stay focused on your mission, even in times of change and uncertainty.
• Stick to your mission and articulate need despite COVID
• Having patience and understanding is key. Research might slow due to COVID restrictions and the overall landscape may look slightly different. Use this as an opportunity to think differently about past paradigms and come up with novel solutions.
• Tend to your cyber security!
• We ask for wire information in our application, so that is one area we felt prepared prior to the pandemic - we were already set up for paperless grant agreements and payments.
• Reach out to grantees to learn what they need and how best to support them
• Have a remote working and virtual event policy in place.

Diversify Funding Strategies
• Have a diverse fundraising program. Because we had other sources, i.e. individual giving, corporate and foundation support, we are in better shape
• Make sure you have a diverse fundraising strategy

Q 61. What question(s) would you like to ask your peer organizations?
• Will you continue to offer more virtual/hybrid meetings instead of going back to traditional in-person meetings.
• What are effective strategies for onboarding new staff and introducing them to your organizational culture?
• It would be great to have a repository for resources. I would especially love to see copies of grantee surveys that have been sent out.
• What will your return to office approach look like? What additional support did you provide to your staff in order to support remote working? What changes were you forced to enact that ended up working out well? Was the Paycheck Protection Program important to you? (if you were eligible of course)
• How are you managing employees who are just not as productive or are just not handling tele-commuting?
• I’d like to know how many organizations that were forced to remote working plan to maintain a remote or hybrid work environment and what changes they have or plan to make to mitigate many of the challenges in communications and workplace dynamics that we faced during the pandemic.
• What is the % of org that will stay fully virtual? How do other organizations deal with staff exhaustion?
• Are you revisiting your strategic plan due to the crisis?
• How are they handling return to work in post-covid era?
• Any success stories with converting in-person fund raising activities to virtual?
• How are you approaching planning? for the coming FY and beyond. What assumptions are you making about travel and in-person events? Will all events need to be hybrid going forward?
• Has the Pandemic made you consider partnerships or collaborations that you wouldn’t have considered before.
• Do you think you can survive with only virtual fundraising?
• Whether they have faced similar issues.
• What does the new normal look like in regard to remote working versus in person, especially with an eye toward equitable treatment of all staff members
• Are you worried about the mental well-being of your funded scientists and, if so, what are you doing about it?
• What does a "return to normal" look like for your organization? What changes have you implemented during the pandemic that you will keep? Which changes will you get rid of?
• How they are navigating discussions about potential return to work, and dealing with continued uncertainty
• What have been some of your biggest learnings, and what do you hope to carry forward beyond COVID.
• How do you deal with grantees who needed to pause research but continue to pay staff in order to keep them for when in-lab research resumed? No-cost extensions are one thing, but what about extra cost extensions?
• What does a long-term hybrid in-person and remote solution look like for you for both office work and collaboration meetings?
• again - I can't think of any questions. does this reflects the more insular thinking that comes from long-term remote work?
• How they have been intentional about fostering positive organizational culture during the pandemic.
• Will other funders go back to in person review meetings (some or all) or have they found the expense and burden on reviewers is not worth the added benefits?

Q 62. Which of the following best characterizes your organization's fiscal year?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Different than the calendar year (e.g. July - June)</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>Same as the calendar year (January - December)</td>
<td>15</td>
<td>3</td>
</tr>
<tr>
<td>No Response</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

Q 63. What is the approximate size of your organization?

<table>
<thead>
<tr>
<th>Fundraising</th>
<th>Societies</th>
<th>Endowment</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;50 employees</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>51-100 employees</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>101 - 500 employees</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>501 - 1000 employees</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>1000+ employees</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>No Response</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>
Q 64. What was the size of your annual budget in your last full fiscal year prior to COVID-19? (In millions) (Note: this information will only be used for demographic analysis purposes.)

Min 0.08
Max 900.00
Average 96.66

Q 65. When should we next repeat this survey?

<table>
<thead>
<tr>
<th>Count</th>
<th>% of Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>In 6 months</td>
<td>8</td>
</tr>
<tr>
<td>In 1 year</td>
<td>23</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
</tr>
<tr>
<td>Never</td>
<td>1</td>
</tr>
<tr>
<td>Don't Know</td>
<td>10</td>
</tr>
</tbody>
</table>

Q 68. Is there anything else that you would like to share?

- This survey is far too long – please limit to more than 5-10 questions. Our team has spent 2+ hours addressing these questions and the scope of the questions asked is highly variable. There are not straightforward answers for many of these questions given the size of our organization.
- Only silver lining is forced some reorganization that needed to happen
- Thank you for the work you do!
- Truly this has been a time that has required people to think outside the box in maintaining connectivity within an organization. It has brought me joy recognizing our organization continuing to strive to achieve goals, and realizing their own potential to achieve goals and work towards improving the health and lives of others amidst a crisis.