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Letter from Executive Director

Brian Callanan, M.Ed.
The recent challenges presented by the COVID-19 pandemic have proven the resiliency of the Cystic Fibrosis Lifestyle Foundation (CFLF), along with donors, volunteers and staff maintained the highest standards of commitment through such a difficult and trying time. From the outset of the pandemic and the impacts on events and fundraising efforts, the CFLF braced for a multi-year struggle.

With advanced preparation, and immediate organizational response, difficult decisions were made to assure the sustainability through an economic downturn resulting from such a global shock. However, adaptation was also needed to expand the avenues and mechanisms for continuing to aid the CF community when it was needed most. Collaboration, creativity and determination helped new bridges be built to provide assistance that would not have existed otherwise.

The period of quarantine also provided the CFLF an opportunity to work internally on reshaping the strategic plans, assessing infrastructure needs and streamlining financial records for simplified tracking and reporting. In looking forward to the 20th anniversary of the CFLF, persevering such a prolonged and widespread challenge was the only option.

As is the mission of the CFLF, transforming such challenging forces into greater determination and resilience is what equates to living STROLO! The results of such tenacity on the part of donors, sponsors, partners and volunteers have positioned the organization for continued perseverance in the third decade ahead.

Thank you to each and every one of you who have enduring commitment to the CFLF in the past, present and future toward making this organization a resource continually growing it’s reach.

Sincerely,

Brian
The mission of the CFLF is to empower people living with cystic fibrosis (CF) to live stronger and longer through healthy and active lifestyle.

Our Vision

The CFLF envisions a new era where people with CF live their best lives, fully empowered, going above and beyond the perceived limitations of life with CF.

Our Mission

The mission of the CFLF is to empower people living with cystic fibrosis (CF) to live stronger and longer through healthy and active lifestyle.
COVID-19 Organizational Effects
During the initial rise of COVID-19 cases in the United States, the CFLF decided to create virtual programming and events.

Fun and free challenges were promoted throughout the CFLF audiences including the “Big Puff TP-Challenge” of blowing on a piece of toilet paper for 30-seconds to hold it against a wall, STROLO Bingo with weekly exercise challenges to win prizes, and the STROLO Movie Nights held each Friday to watch streaming movies together while actively chatting online.

Our STROLO University program became a safe place for the CF community to come together and ‘hang out’ by providing exercise classes such as yoga, dance, and pilates. We also had meditation, story telling, art, music, and cooking classes. In addition to all those classes we had sponsor based classes and practitioner corner which were more educational.

On top of our virtual program, we included a virtual element to our Champs Challenge fundraising event so that anyone could join from any state.

Lastly, we created another virtual event called Virtual Paint Night. This event was geared towards having fun while creating art with the CF community during a time of uncertainty.
2020-21 Program Impact
Recreation Grants were awarded to 107 people with CF in 2020, and to 137 in 2021. For nearly 15 years, this program has helped families and individuals faced with CF to overcome financial barriers to exercise and recreational activities.

STROLO University was created in response to the COVID-19 pandemic providing online classes and activities for STROLO University a series of online activities, exercises and classes to provide the opportunity to build community and learning through healthy activities.

CFLF blogs Is an integral part of building the CFLF community by offering a platform for members of the CF community to express themselves and share their experiences through the art of storytelling.

STROLO Star is an initiative to showcase some of the amazing journeys of grant recipients who shine as bright as stars going above and beyond all expectations with their passion and chosen activity. Watch these inspiring interviews exclusively on our YouTube Channel.
Summary of Recreation Grants:

The CFLF intention in approving a Recreation Grant request is to encourage and support access to activities that challenge the body and the lungs physically, while also providing mental, social and emotional benefit to people living with cystic fibrosis.
Grant Recipient Stories
CARTER BLANCHE
KARATE CLASSES - 2021
“We have seen a huge improvement in Carter’s stamina in karate class and outside of class. His lung health is phenomenal and one of our ultimate goals is to sustain his lung health and overall respiratory health as long as possible.”

NORI BOEHOLT
KICKBOXING - 2021
“When I kickbox I feel empowered and strong. I feel that I can conquer any challenge I may face. This helps me with my health not only because it is great exercise but gives me confidence that I can handle the battles I may face in the future.”

KIMBERLY FULLER
HORSEBACK RIDING - 2021
“Not only is it good exercise to go riding but it is very good for my mental health as well. I feel a sense of peace and calm while I am horseback riding. Being out in the fresh air is great for my cystic fibrosis, especially with all that bouncing it is like doing my vest treatment.”
Madison Rowley (Dance) 2020

“I don’t let cystic fibrosis stop me or define me. My passion is dancing and having fun. I have so, so, so much fun at the dance project. Dancing gives me so much exercise and strength, and that is so helpful to keep my lungs clear and healthy.”

Joshua Marchant (Golf club) 2020

“I would benefit from receiving a Recreation grant from the CFLF because it would further my passion and love for golf. Without worrying about the prices and expenses of golf, I could go out there and enjoy the sport, improve my game and better my physical health at the same time.”
United States

During 2020-21, the CFLF awarded CF Recreation Grants in 39 out of 50 states including:

- 8 States with 1 grant awarded:
  - Delaware, Georgia, Idaho, Iowa, Montana, Nebraska, New Mexico, & Virginia

- 15 States with 2-5 grants awarded:
  - Arkansas, Colorado, Indiana, Kansas, Louisiana, Maryland, Massachusetts, Michigan, Mississippi, New Hampshire, New Jersey, Rhode Island, South Carolina, Vermont, & Washington

- 11 States with 6-10 grants awarded:
  - Connecticut, Illinois, Kentucky, Maine, Minnesota, Missouri, North Carolina, New York, Oregon, Utah, & Wisconsin

- 4 States with 11-20 grants awarded:
  - Florida, Ohio, Pennsylvania, & Texas

- 1 State with 20+ grants awarded
  - California

Canada

During 2020-21, the CFLF awarded CF Recreation Grants in 2 of the 10 provinces (in Alberta and Ontario).

- Ontario (ON) 5 awards
  - 3 Gym Memberships
  - 1 Horseback Riding Lessons
  - 1 Yoga Classes Membership

- Alberta (AB) 2 awards
  - 1 Gym Membership
  - 1 Fitness Training Course
CANADA

MAP OF OUR REACH

LEGEND

- NO GRANTS
- 1-2 GRANTS STATES
- UP TO 5 GRANTS
- UP TO 10 GRANTS
- UP TO 20 GRANTS
- 20+ GRANTS
STROLO University is a virtual program that began during COVID 2020, as a place for the CF community to do things together such as exercise classes, meditation, art, music, cooking, education classes, etc.

**2020**
- Anonymous donations: $3,955
- Participants: 175
- Course Topics Included:
  - Story Telling
  - Hip Hop Dance Class
  - Positivity and Awareness
  - Cooking
  - Indoor Cycling
  - Yoga

**2021**
- Donation: $3,883.71
- Viewership: Facebook Live and Zoom
- Course Topics Included:
  - CF Community Resources
  - Professional Development
  - The Cutting Edge Research
  - HCP Educational Corner
  - Indoor Cycling
  - Well Being
  - CF Kids Corner
  - Get Fit (Workout series)
  - Quick Bites
The CFLF Blog was originated in 2011, and to date has posted more than 900 articles on a multitude of topics relating to leading life with CF as a ‘lifestyle’. Currently topics are focussed on a monthly schedule relating to chronological dates.

40 Blog posts in 2020
35 Blog posts in 2021

Authors are solicited throughout the year with both recurring and ongoing submissions by one-time authors. The range of topics includes goal setting, dietary/recipes, travel with CF, psychosocial issues, CF Awareness, family and relationships, mental health, back to school, exercise and holiday related stories.
Getting Through This

We realize this is an unprecedented time in our nation, and across the world, as we face a pandemic which greatly affects so many people, those with Cystic Fibrosis are one of the most vulnerable. For people with CF, every precaution should be taken to reduce exposure and help prevent infection. The Cystic Fibrosis Foundation has provided the community with information and answers to some of the questions you may have about COVID-19, and how to best prepare yourself and loved ones in these challenging times.

CF Mom in Charge. Rest Easy.
The passion these ladies show for the cause is remarkable. To take the time away from their lives to battle against a disease that affects 30,000 individuals in this country is nothing short of inspiring. Needless to say, the passion and leadership displayed by these three women in Wichita, Kansas, in regards to CF, also makes plays hugely into their rolls in their mid-American community.

Pace It Like A Swim Practice!
I am not naturally athletic, but I found my sport at an early age: swimming. I will never be the fastest swimmer in the pool, but that doesn’t take away from my love of being in the water. The best part of swimming is that the water takes you as you are. I know that if I’m happy, hurting, or am somewhere in between, the water is unbiased and will take me as I am. It may be an odd sport in the grand scheme of things, but going to practice is the best part of my day.
We're stronger than we look.
Okay some of us are lucky enough to look noticeable strong, but the strength I'm talking about is more of a mental strength. We take that strength and somehow transform it into superhuman physical strength. It’s like when you hear about a person who come upon an accident where a car has flipped over and there are people inside and without even thinking that person is somehow able to lift the car up off the ground to get the people out. It doesn’t make logical sense in the least. Sometimes CF feels like having to lift that car up, over and over again. It doesn’t make sense, but somehow we do it.

We hate wasting time.
Time is very important to us and wasting time is the worst. Imagine being told at a young age that you most likely won’t live past 14. Then making it to 14 and having someone tell you that you won’t live past 25. This makes a person feel like they’re in a race with the clock. I’ve never known anyone with CF who is comfortable with letting time slip by without living it completely, because really, CF or not, you never know what will happen in a day.

We think A LOT.
We have a lot of downtime to think, like while we’re doing our treatments three time a day, or sitting in waiting rooms, or in the hospital, or standing in line at the pharmacy. We think and plan make mental lists and worry and wonder and then think about how much we’re thinking. It never ends.
STROLO Star is a program that features a grant recipient who has been living the strolo lifestyle. Check out their videos below by clicking the names!

Kyle O’Tain 2020
Hear an inspirational story of Kyle’s recovery and determination to live an active lifestyle post transplant, stopping at nothing to reach his goals with achievements to show.

Rosie Grossbaum 2021
Learn about this amazing teen’s story of triumph against the odds with her passion for dance.
Trailblazer whose life before and after translate is an amazing testament to perseverance as a double-lung transplant recipient and a grant recipient.

A snowboarder with CF who goes about and beyond her illness in her active lifestyle.
Our Reach
Outreach and Visibility

○ Collaborations
  ■ Cystic Fibrosis Engagement Network
  ■ Recreation Grant Collabs (Miles 4 CF, Dieruf Memorial Fund)
○ CF Education Days
2020 - Total $572,746

Gross Income Sources

- **GRANTS**
  - 59.4%

- **FUNDRAISING EVENTS**
  - 19.9%

- **SPONSORSHIPS**
  - 8.4%

2021 - Total $252,458

- **GRANTS**
  - 22.9%

- **FUNDRAISING EVENTS**
  - 22.9%

- **SPONSORSHIPS**
  - 59.4%
<table>
<thead>
<tr>
<th>Description</th>
<th>2020</th>
<th>2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>STROLO Program Expenses</td>
<td>$2,475</td>
<td>$641</td>
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<tr>
<td>Individual Recreation Grants</td>
<td>$55,305</td>
<td>$40,905</td>
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<tr>
<td>Loretta Morris Fund Grants</td>
<td>$8,835</td>
<td>$7,522</td>
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<td>Peer Support Awards</td>
<td>$6,836</td>
<td>$8,306</td>
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<tr>
<td><strong>Total Recreation Grant Program</strong></td>
<td>$70,990</td>
<td>$56,732</td>
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<tr>
<td>Accounting</td>
<td>$4,500</td>
<td>$8,225</td>
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<td>Bulk Mailing</td>
<td>$474</td>
<td>$3,424</td>
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<td>CF Awareness Mailing</td>
<td>$3,254</td>
<td>$0</td>
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<td>Liability Insurance</td>
<td>$1,575</td>
<td>$1,575</td>
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<tr>
<td>Marketing / Website / Social Media Ads</td>
<td>$31,913</td>
<td>$7,494</td>
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<td>Office and Administrative</td>
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<td>$9,701</td>
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<td>Organizational Expansion</td>
<td>$4,375</td>
<td>$624</td>
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<td>Payroll - Taxes</td>
<td>$12,063</td>
<td>$16,128</td>
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<td>Payroll Expenses w/ Benefits</td>
<td>$150,105</td>
<td>$204,464</td>
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<td>Payroll Service Fees</td>
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<td>$5,486</td>
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<td>Postage</td>
<td>$821</td>
<td>$497</td>
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<td>Rent and utilities</td>
<td>$6,348</td>
<td>$3,418</td>
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<tr>
<td>Supplies &amp; Software</td>
<td>$9,554</td>
<td>$0</td>
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<td>Telecommunications</td>
<td>$4,241</td>
<td>$5,333</td>
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<tr>
<td>Travel and Related Expenses</td>
<td>$527</td>
<td>$2,066</td>
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<tr>
<td><strong>Total Management &amp; Gen'l Expense</strong></td>
<td>$242,777</td>
<td>$262,119</td>
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<tr>
<td>Fundraising Event Related Expenses</td>
<td>$21,992</td>
<td>$32,878</td>
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<td><strong>Total Expenditures</strong></td>
<td>$350,966</td>
<td>$352,369</td>
</tr>
<tr>
<td>Net Revenue</td>
<td>-$98,317</td>
<td>$220,703</td>
</tr>
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</table>
COVID-19 Impacts

- 2020 reflected unforeseeable cancellations of fundraising activities resulting in abnormally low revenue.
- Emergency Relief grants and fundraising in anticipation of fundraising activity suppression were received in 2021 generating an abnormally high revenue.
- The revenue of 2020-21 averaged $412,600 per year.

The Management & General expenses are internally classified into Programming, Fundraising and Support in alignment with the CFLF’s Articles of Incorporation.

The two-year expenses were fairly level incorporating balanced variables

2020
- Lower staffing gradually ramped back up
- Greater investment in technology and virtual fundraising, marketing and investment in website development

2021
- Greater staffing capacity and program development
- Lower software and technology costs primarily absorbed in previous year
Marketing Statistics & Analytical Data
Social Media Performance

**OVERVIEW**

**Twitter**
- 1,097 Followers
- Non-active posting schedule

**Facebook**
- **Paid Promotions:**
  - STROLO University start of classes
  - Champ’s Challenge
  - Holiday Cards
- **Calls to Action [posts]**
  - Holiday Giving
  - CF Awareness month
- **Awareness Campaigns**
  - Donate Life awareness month
  - CF Awareness Month
  - Rare Disease Day
- **etc.**

**Instagram**
- **Paid Promotions:**
  - STROLO University start of classes
  - Champ’s Challenge
- **Calls to Action [posts]**
  - Champs Challenge
  - Giving Tuesday
  - Holiday Giving
  - CF Awareness month
- **Awareness Campaigns**
  - Donate Life awareness month
  - CF Awareness Month
  - Rare Disease Day
  - etc.
Facebook Analytics 2020-21

First Impressions
Facebook reach spiked past 40k in May due to CF awareness posts & STROLO-U posts.

RAISING AWARENESS ONLINE

The large spike on Facebook indicates that STROLO University program spring semester had begun.

The following two spikes were from continued STROLO U classes as well as CF Awareness month posts.

Page and profile visits
Facebook Page visits
3,055 ▲ 300.9%

How people interact with us

14TH ANNUAL
2021 CHAMP'S CHALLENGE
BENEFIT FOR CYSTIC FIBROSIS

Facebook profile visit spikes past 60 occurred due to STROLO U spring semester in May and CF awareness posts. The following spikes occurred due to STROLO U fall semester and Champs challenge posts.

26,000 LIKES !!!

New likes and follows
Facebook Page new likes
227 ▲ 1.04%

How people interact with us

Reach
Facebook Page reach
253,642 ▲ 2.0%

First Impressions
Facebook reach spiked past 40k in May due to CF awareness posts & STROLO-U posts.

RAISING AWARENESS ONLINE

The large spike on Facebook indicates that STROLO University program spring semester had begun.

The following two spikes were from continued STROLO U classes as well as CF Awareness month posts.
Paid Advertisements on the Business Suite

The ‘Paid Ads’ feature in the Facebook Business Suite allows for non-profits to extend their reach to new audiences across their platform increasing awareness and visibility of the CFLF activity and outreach.

**What are “impressions”? And what does it mean?**

An “impression” of a social media page is when any form of content enters the screen of a person’s Facebook account, even if the person is not engaging or looking at it.

Facebook measure these impressions by introduces our content to new people through a direct ad, and a passive approach.

Side by side comparison of amount spent on advertising and the ROI in the form of views, reach, and impressions. The highest return was at the end of May with a spike of 60k interactions with a live STROLO-U Class.
Instagram Performance

Expanding Our Reach on Instagram

Instagram reach spiked almost to 10k in May due to CF awareness posts and STROLO U. It also spiked in September for STROLO University posts.

Views and Impressions

Instagram profile visit spikes up to 80 occurred due to STROLO U spring semester in March and April.
Top Performers

Highest performing videos on Facebook and other social media platforms.

1500th Grant Recipient Kira Taylor story performed exceptionally well across platforms.

In-person and virtual hybrid event of Champs Challenge received great reach across social media.
Fundraising 2020-21
As a 501(c)3 non-profit organization, the CFLF relies on the generosity of individual contributions through events, online campaigns and direct mailing efforts. The COVID-19 pandemic had a significant impact on the world, with financial effects resulting in a tidal rise and lowering of fundraising revenues.

The first year of the pandemic, 2020, resulted in several emergency grants helping to sustain the operations of the CFLF with several cancelled events. The focus of efforts shifted from event coordination to virtual campaign and program developments. The surge of funds received early in the pandemic was utilized throughout the ongoing challenges on fundraising throughout subsequent years.
<table>
<thead>
<tr>
<th>Location</th>
<th>Event Name</th>
<th># Donors</th>
<th>$ Gross Raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online (national)</td>
<td>Valentine's Day Card (e-card sales)</td>
<td>5</td>
<td>$160</td>
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<tr>
<td>South Tahoe, CA</td>
<td>STROLO Tahoe CF Winterfest (ski/board retreat)</td>
<td>50</td>
<td>$20,112</td>
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<tr>
<td>Online (national)</td>
<td>STROLO Bingo (exercise bingo)</td>
<td>59</td>
<td>$113</td>
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<tr>
<td>Tampa, FL</td>
<td>STROLO Strut (pickleball tourney)</td>
<td></td>
<td>$4,370</td>
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<tr>
<td>Online (national)</td>
<td>STROLO University (online classes)</td>
<td>175</td>
<td>$3,935</td>
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<tr>
<td>La Jolla, CA</td>
<td>KnockOut CF West (circuit HIIT)</td>
<td></td>
<td>$16,000</td>
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<tr>
<td>Mail/Online (national)</td>
<td>CF Awareness Month</td>
<td>19</td>
<td>$1,938</td>
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<tr>
<td>Virtual Only (national)</td>
<td>Champ’s Challenge (bike/run)</td>
<td>377</td>
<td>$49,403</td>
</tr>
<tr>
<td>New Castle, CA (local)</td>
<td>STROLO@Dono (cornhole tourney)</td>
<td>(11)</td>
<td>$3,825</td>
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<tr>
<td>Sugarbush, VT</td>
<td>New England Craft Beer Open (golf tourney)</td>
<td></td>
<td>$5,000</td>
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<tr>
<td>Online (national)</td>
<td>Giving Tuesday</td>
<td>7</td>
<td>$13,772</td>
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<tr>
<td>Mail (national)</td>
<td>Holiday Mailing</td>
<td>49</td>
<td>$6,008</td>
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<tr>
<td>Virtual (national)</td>
<td>Special Events (pop-up events)</td>
<td>257</td>
<td>$5,760</td>
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<tr>
<td>Donor Hosted (global)</td>
<td>Facebook Fundraisers</td>
<td>165</td>
<td>$2,819</td>
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Events and Campaigns 2021
Total - $55,933

<table>
<thead>
<tr>
<th>Location</th>
<th>Event Name</th>
<th># Donors</th>
<th>$ Gross Raised</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online (national)</td>
<td>Valentine’s Day (e-card sales)</td>
<td>7</td>
<td>$153</td>
</tr>
<tr>
<td>Online (national)</td>
<td>Virtual Paint Night (group painting)</td>
<td>74</td>
<td>$5,237</td>
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<tr>
<td>Online (national)</td>
<td>STROLO University (online classes)</td>
<td>132</td>
<td>$3,935</td>
</tr>
<tr>
<td>Online (national)</td>
<td>Champ’s Challenge (virtual bike/run)</td>
<td>52</td>
<td>$6,610</td>
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<tr>
<td>Online (Boston, MA)</td>
<td>KnockOut CF (circuit HIIT)</td>
<td>4</td>
<td>$1,500</td>
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<tr>
<td>Online (national)</td>
<td>CF Goes Big (talent show)</td>
<td>7</td>
<td>$5,000</td>
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<tr>
<td>Online</td>
<td>Giving Tuesday</td>
<td>32</td>
<td>$1,237</td>
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<tr>
<td>Mail (national)</td>
<td>Holiday Mailing</td>
<td>58</td>
<td>$6,714</td>
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<td>Online (national)</td>
<td>Holiday Cards (custom card sales)</td>
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<td>$379</td>
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<td>Virtual (national)</td>
<td>Special Events (pop-up events)</td>
<td>63</td>
<td>$3,081</td>
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<tr>
<td>Donor Hosted (global)</td>
<td>Facebook Fundraisers</td>
<td>227</td>
<td>$5,358</td>
</tr>
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Photos / slideshows from events
2020 Programs and Events

- First Virtual Champs Challenge
- Knock Out CF
- First Semester of STROLO-U
- STROLO University
- CF Blog
- Sponsored Medical Presentations
2021 Programs and Events

Happy Holidays!

From the Recreation Grant Recipients - Thank You for Your Donation!

Cystic Fibrosis Lifestyle Foundation

Champs Challenge NY

14er Hike on Mt. Sherman CO

Valentine's Day Fundraiser

Holiday Card Fundraiser

STROLO University Fall Semester

Virtual Paint Night

Feb. 28, 2021
3pm - 6pm
Sign up via link: cff.org/paint
Thank You To Our Partners!

Vertex

Chiesi

Gilead

Viatris

AbbVie

Translate

Kroger

Nestle Health Science