



2020 ANNUAL REPORT

Fiscal Year 2020 (Oct 1, 2019 - Sept 30, 2020)

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MISSION

Inspire the Rare Disease Community with hope through the power of sport



VISION

Empower people to take action against rare diseases and be a catalyst for the medical community to find cures



Dear Friends,

2020 has certainly presented its fair share of challenges and no amount of planning can prepare us for all the obstacles we face in our daily lives. As many of our friends in the Rare Disease Community know well, we must always persevere. I am proud of our team and grateful for the support that we received allowing us to accomplish significant organizational milestones in the face of ongoing uncertainty presented by the global COVID-19 pandemic.

The Young Investigator Draft is marking its 3rd year and is our cornerstone event for funding rare disease research and celebrating rare disease researchers. With the commencement of the 2020 Young Investigator Draft, Uplifting Athletes has now funded 18 different researchers with over \$300,000 in early stage rare disease research grants since 2018.

Inspiring hope in the Rare Disease Community is an important part of our mission. One way we achieve this is through recognition of rare disease champions. Now in its twelfth year, we recognize a Rare Disease Champion Team who are using their platform in college football to inspire hope in the Rare Disease Community. In March, we recognized 5 undeniably impactful stories at the Maxwell Football Club Awards Gala and the Young Investigator Draft at Lincoln Financial Field.

With the forced cancellation of all but one Lift For Life events (Stony Brook) due to the pandemic, the Uplifting Athletes team pivoted to develop a new virtual initiative, the 7,000 Mile Challenge. The 7,000 Mile Challenge was a monumental success in its inaugural year and an initiative that will be around long after the pandemic passes. The Uplifting Leaders program rose to new heights with the addition of Levi Norwood as the Chapter Success Manager, increasing the number of chapters to participate in Touchdown Pledge Drive (17) and a record attendance (40) at our Leadership Development Conference.

Our organization is encouraged by the perseverance of our team and the Rare Disease Community. We are humbled by all of those that have continued to support Uplifting Athletes this year. We will play our part in inspiring hope to those impacted by rare diseases through the power of sport and continue to grow to be the best that we can be for the people of the Rare Disease Community.

With hope and love,

Robert Long
Executive Director



Built on the vision of one person and pulling from his family's rare disease experience as the foundation, former Penn State University football player and student Scott Shirley founded Lift For Life® in 2003 before launching Uplifting Athletes in 2007.

Since Day 1, Uplifting Athletes has focused on using the platform of college football to shine a spotlight on the rare disease cause while providing the student-athletes we are engaged with a valuable leadership experience.

Uplifting Athletes provides an opportunity for our student-athletes to enhance the valuable skills they develop on the college football playing field and hone in on transferable life and leadership skills that are necessary for careers after athletics.

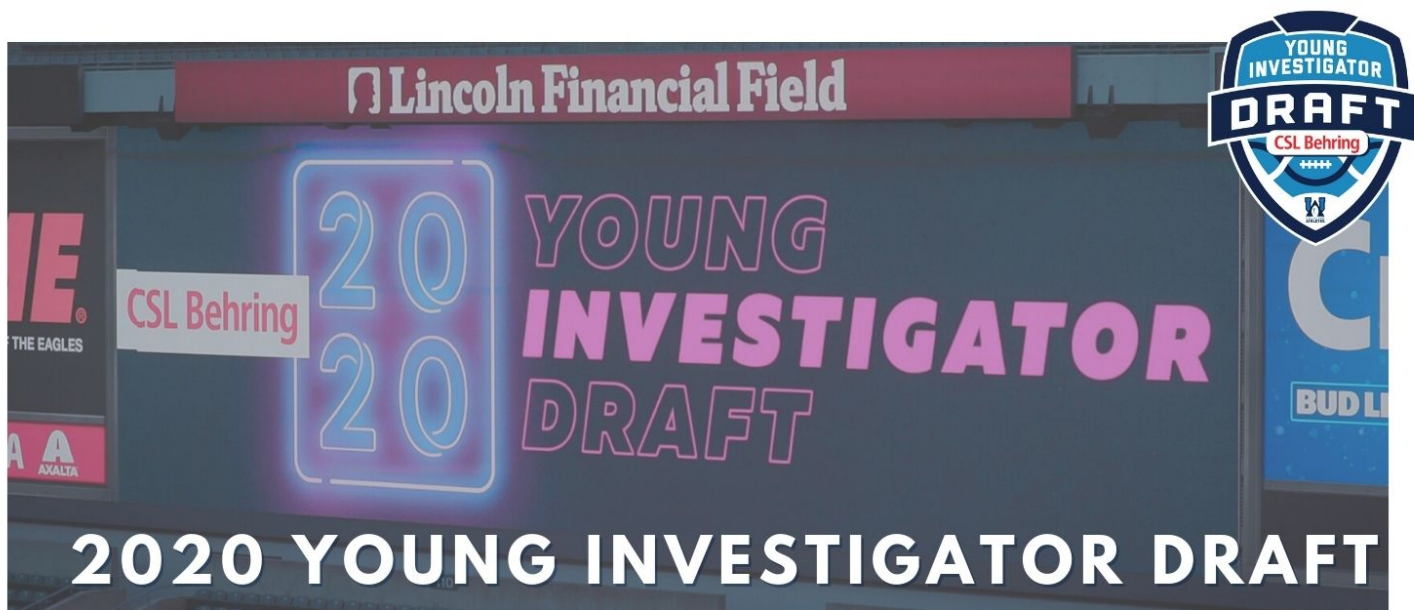
More than a dozen years later, the cause is still the same. Though today, the organization has expanded its reach to include a network of athletes that consists of college football student-athlete led chapters, Uplifting Ambassadors and Team UA participants.

All the annual events and fundraisers associated with Uplifting Athletes fuel our commitment to create Uplifting Leaders, engage in Uplifting Experiences, fund Rare Disease Research, and expand Rare Disease Awareness.



"So many people don't have a voice to make a difference. I've learned that I am blessed with an amazing platform to help those in need."

Lehigh Chapter Vice President and tight end Alex Snyder



The Young Investigator Draft presented by CSL Behring is the result of Uplifting Athletes' ongoing commitment to cultivate resources that accelerate scientific advancements for rare disease treatments and potential cures while facilitating the next generation of rare disease researchers.

Young Investigator Draft grants fund research that is collaborative and translational in order to positively impact treatments and potential cures for the entire Rare Disease Community.

Uplifting Athletes has provided more than \$300,000 in funding to rare disease researchers through its first three Young Investigator Drafts.

CSL Behring



"A grant like this allows us to push the boundaries and try the cool and untested ideas that are not likely to be funded by the larger agencies. It's the encouragement we get to dare to try some things like nobody has ever before."

Dr. Abhishek Mangaonkar



Dr. Joshua Brandstadter
Castleman Disease
 Castleman Disease Collaborative
 Network



Dr. Kathryn Hixson
Malan Syndrome
 University of North Carolina at
 Chapel Hill Catalyst for Rare
 Diseases



Dr. Cheng Cheng
Rare Cancers
 University of California, Irvine



**Dr. Abhishek
 Mangaonkar**
*Dyskeratosis Congenita and
 Telomere Biology Disorders*
 Mayo Clinic



Dr. Jonathan Whittamore
Primary Hyperoxalurias
 University of Florida



Dr. Benjamin Chan
*Collaborative Research
 Grant*
 Emily's Entourage



Powered by Sanofi Genzyme, the Rare Disease Champion Team is part of the National College Football Awards Association (NCAA), and celebrated as part of the Uplifting Athletes' Young Investigator Draft in Philadelphia.

Members of the annual Rare Disease Champion Team are leaders in college football who realized his or her potential to make a positive and lasting impact on the Rare Disease Community. The team concept is to ensure inspiring rare disease stories of qualified leaders in college football are shared and celebrated.

Sculpted by world renowned artist Brian Hanlon, the Rare Disease Champion trophy is in the likeness of Mark Herzlich, the former Boston College and New York Giants linebacker who provided the inspiration for the award after overcoming a life threatening battle with the rare disease Ewing's sarcoma in 2009.





UPLIFTING LEADERS

The catalyst for the Uplifting Leaders Program is the annual Leadership Development Conference. We encourage two leaders from each current and prospective chapter to attend this two-day conference focused on the development of transferable life skills, rare disease advocacy and leadership.

In 2020, 40 college football student-athlete leaders from 20 chapter and prospect universities attended the late-January conference in Atlanta, Georgia. Our Leadership Development Conference is a unique rare disease education initiative for student-athletes to learn to maximize their platform on their campus to raise awareness on behalf of the Rare Disease Community.

The skills the student-athletes develop at the conference are applied through managing the chapters on campus. This provides a much needed internship-like experience for student-athletes that otherwise would have to sacrifice offseason training in order to obtain a competitive internship.



"Uplifting Athletes supports a great cause that is personal to me because I have had family members pass away from rare diseases. It is so important to support young rare disease researchers because it is difficult for them to have access to funding.

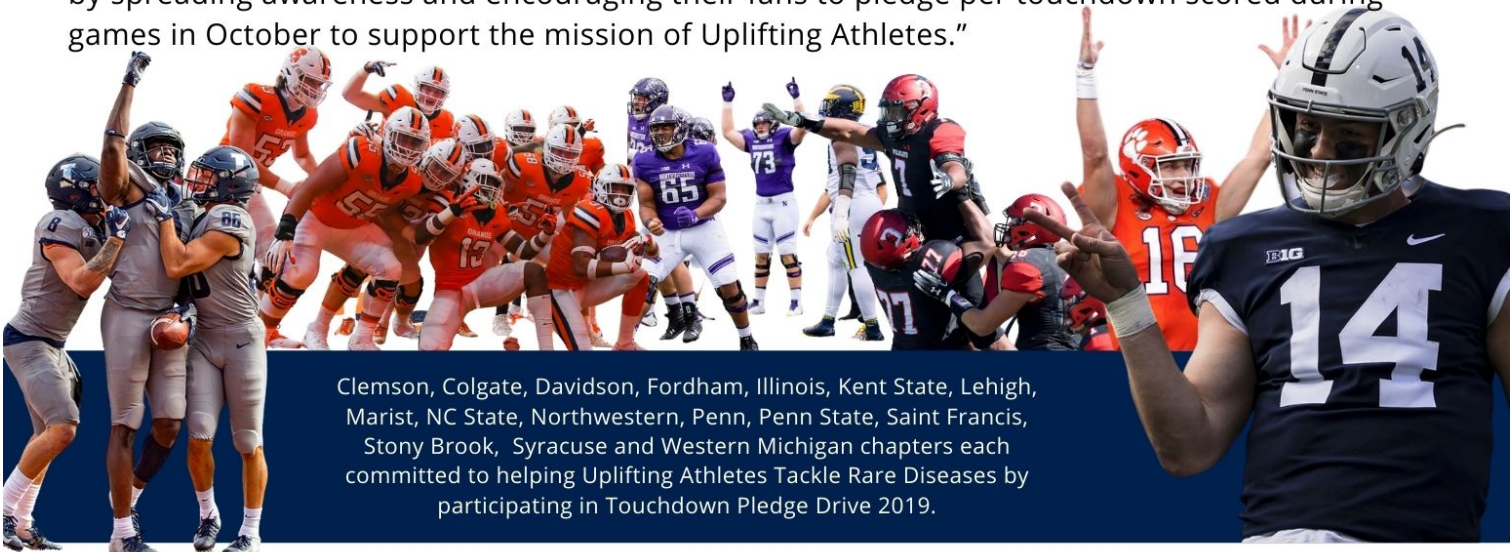
Colgate Chapter President and quarterback Jake Froschauer



Every touchdown scored during the month of October by participating members of the Uplifting Athletes network of college football student-athlete led chapters helped raise funds and awareness for the Rare Disease Community. Through the 17 participating chapters, the 2019 Touchdown Pledge Drive, **\$15,295** was raised to support to support the Rare Disease Community.

Uplifting Athletes chapters are run by college football student-athletes. So, for fans, this is a great way to support the players on your favorite team in their off-the-field efforts by supporting their on-field performance.

“Uplifting Athletes’ college football chapters provide a unique platform to raise awareness for the Rare Disease Community. Touchdown Pledge Drive is an in-season student-athlete led initiative to shine a national spotlight on rare diseases,” Uplifting Athletes Director of Sports Impact Brett Brackett said. “We are grateful to each and every school that participated this year by spreading awareness and encouraging their fans to pledge per touchdown scored during games in October to support the mission of Uplifting Athletes.”



Clemson, Colgate, Davidson, Fordham, Illinois, Kent State, Lehigh, Marist, NC State, Northwestern, Penn, Penn State, Saint Francis, Stony Brook, Syracuse and Western Michigan chapters each committed to helping Uplifting Athletes Tackle Rare Diseases by participating in Touchdown Pledge Drive 2019.



People joined the 7,000 Mile Challenge from points all across the United States and overseas, as well, including Germany, Spain, Great Britain and the Philippines, all to rally support for the rare disease cause.

The inaugural 10-day virtual event hosted by Uplifting Athletes in July was centered on inspiring the Rare Disease Community with hope by coming together as one team with a common goal - accumulate 7,000 miles to bring focus and attention to the more than 7,000 rare diseases.

Working together to walk, run, bike, swim or roll on wheels of any kind, the Uplifting Athletes community joined forces and reached the lofty goal of 7,000 miles in only seven days. The 7,000 Mile Challengers didn't slow down when they reached their goal either. They finished strong and posted more than 12,000 miles before the bell rang on the final day.

The challenges faced today by the Rare Disease Community are bigger than any one individual, team or organization can tackle alone. It took the power of rare disease patients, advocates, friends, families, caregivers, football student-athletes, doctors, a gym, a bike riding club, former players and rare disease ambassadors rallying for a cause and goal that could never be accomplished alone.



"When it comes to being rare there's never a cookbook. They are all trailblazers. It's an amazing group of people that live and work in this space."

Justin Hopkin, Rare Disease Doctor, Father, & Advocate

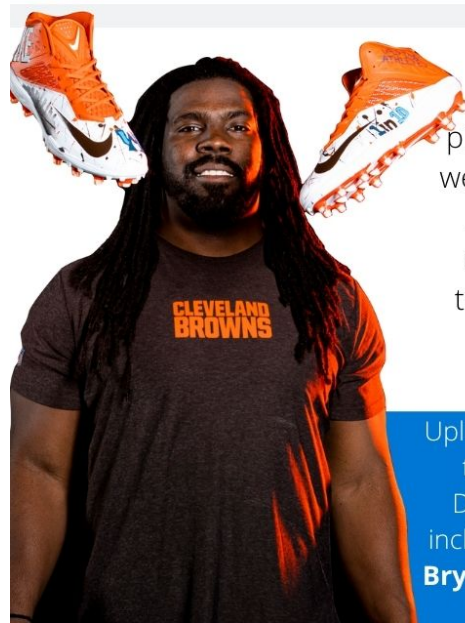
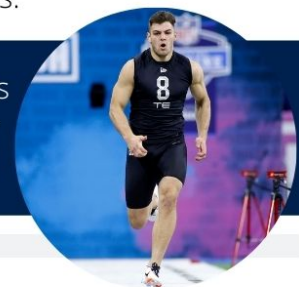


For the sixth consecutive year, Uplifting Athletes empowered NFL prospects with the opportunity to use the NFL Combine or NFL Pro Day as a platform to give back by raising funds and awareness in support of the Rare Disease Community.

The **Reps For Rare Diseases** campaign is one of the first opportunities for these athletes to create an impact using their platform as professional athletes. Uplifting Athletes is excited to work with these outstanding individuals to help them give back during this very pivotal time of their lives.

\$59,455

Amount raised by the 51 NFL prospects who participated in the 2020 Reps For Rare Diseases campaign.



Through the NFL's **My Cause My Cleats** campaign, players across the league support their favorite cause by wearing custom designed cleats representing their cause.

At Uplifting Athletes, we team up with former chapter members turned NFL players and UA Ambassadors to take advantage of this tremendous opportunity to raise awareness for the Rare Disease Community.

Uplifting Ambassadors also includes individual athletes using their platform to impact and inspire others in the Rare Disease Community. During the 2019-2020 season, that included Malik Turner, Nick Allegretti, **Riley Dixon, Brandin Bryant**, Josh Allen, and former Penn State Chapter President Ryan Bates.





The focus and purpose of Uplifting Experiences is to share the spotlight afforded to athletes with rare disease patients, families and caregivers.

Uplifting Experiences included a trip to the College Football Hall of Fame during the Leadership Development Conference with Atlanta area rare disease patients and families. As well as the Hopkins family trip to Buffalo Bills practice to visit with former Penn State Chapter President and current Bills Uplifting Ambassador, Ryan Bates and Rare Disease Awareness Games that involved the Syracuse, Western Michigan, Princeton and Penn Chapters.



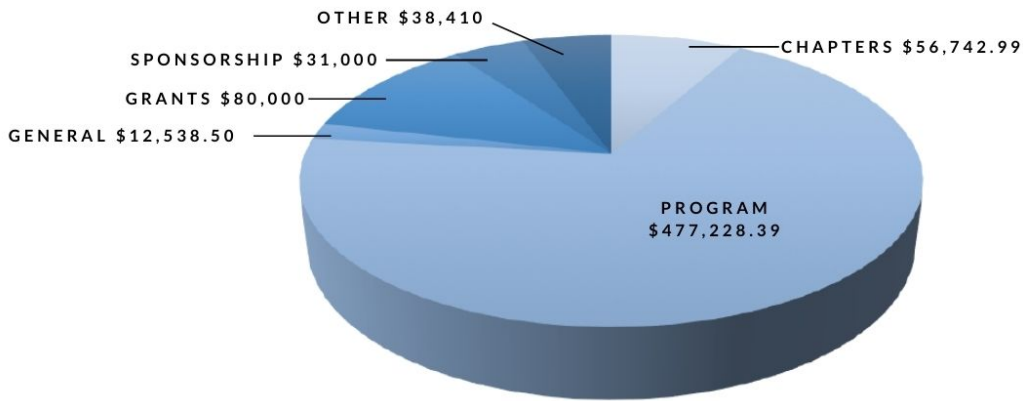
It is important to remember there is more to life than football and being just a football player. The fact I can use my platform to help raise awareness for the Rare Disease Community allows me to help and serve others."

Illinois Chapter President and offensive lineman Alex Palczewski





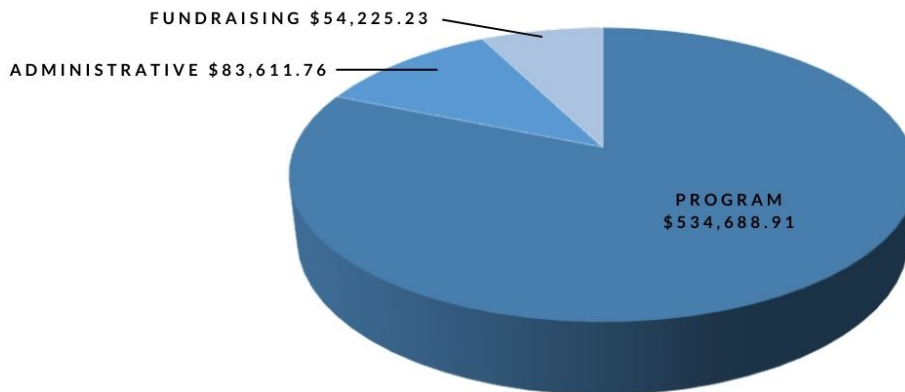
Fiscal Year 2020 - Revenue



Total: \$695,919.88

We take pride in being good stewards of every dollar donated to Uplifting Athletes and work diligently to utilize those funds to carry out our mission.

Fiscal Year 2020 - Expenses



Total: \$672,525.90

*Charts represent unaudited financials for FY2020 (10/1/19 to 9/30/20)



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BOARD



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Scott Schliebner
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Senior Vice President, Centers for Rare Diseases & Digital Therapeutics - PRA Health Sciences



OUR WHY

95%
of rare diseases are without an FDA approved treatment or therapy.

1 in 10 Americans will be diagnosed with a Rare Disease

50%
of people diagnosed with a rare disease are children

7,000
Approximate number of different rare diseases that collectively affect more than 30 million Americans.

It is estimated that 350 million people worldwide suffer from rare diseases

A Rare Disease is one that affects fewer than 200,000 Americans at any given time.



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