



2019 ANNUAL REPORT

**W UPLIFTING
ATHLETESSM**

www.upliftingathletes.org
info@upliftingathletes.org



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,

In the lives of rare disease families, every new day can be considered a milestone. I have had 3,294 milestones as I share this message with you. Each milestone is a blessing. The past year has been particularly special. About one year ago, the board of Uplifting Athletes granted me the opportunity to step in as the Executive Director of this incredible organization. Working off the foundation that Founder Scott Shirley and the Uplifting Athletes staff built has allowed for unprecedented success for Uplifting Athletes in 2019.

We owe a great deal of gratitude to our donors, corporate partners, rare disease advocates and athletes for their belief in our mission to inspire hope throughout the Rare Disease Community by leveraging the power of sport. The eagerness with which we have received support for our programs and initiatives has been humbling. With your support, we have reached new heights throughout the organization.

The Uplifting Leaders program saw our largest number of attendees at our Leadership Development Conference (37) and the most numbers of chapters to participate in Lift for Life (21) and Touchdown Pledge Drive (15) in 2019. Uplifting Ambassadors saw the most participants in our Reps for Rare Diseases campaign (54) and our Rare Disease Research program, through the 2019 Young Investigator Draft, doubled the amount of funds directed to rare disease research to \$120,000.

As we push forward into 2020, we will continue to celebrate our personal and organizational milestones and we want to thank you for making it all possible. Please enjoy this annual report and consider supporting Uplifting Athletes in 2020.



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 four charitable programs: Rare Disease Awareness, Disease Research, Uplifting Experiences and Uplifting Leaders.



"It is an honor to be able to use our platform to help raise awareness and support the Rare Disease Community through Uplifting Athletes. We are all proud to be part of a team that is working so hard to tackle rare diseases."

Nick Rinella, Saint Francis Chapter President & Defensive Back



YOUNG INVESTIGATOR DRAFT

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 \$180,000 in funding to rare disease researchers through its first two Young Investigator Drafts.



"Just like at the NFL Draft where players are chosen, we are giving out research money for these doctors so they can find cures for these rare diseases. We're a team, and as we come together collectively we are all working together to find a cure.

Beth Ann Telford, Brain Cancer Survivor and Advocate



YOUNG INVESTIGATOR DRAFT



Dr. Brenda Gallie
*Collaborative Research Grant
 International Retinoblastoma
 Consortium*



Dr. Elizabeth Harrington
*Rare Muscular and
 Neurological Disorders
 Columbia University Medical
 Center*



Dr. Eugene Hwang
*Rare Cancers
 Children's National Medical
 Center*



Dr. Alberto Japp
*Rare Autoimmune
 Disorders
 University of Pennsylvania*



Dr. Shana McCormack
*Rare Genetics Disorders
 Children's Hospital of
 Philadelphia*



Dr. Brian Sworders
*Rare Blood Disorders
 Stanford University School of
 Medicine*



RARE DISEASE CHAMPION

2019 Rare Disease Champion: Joshua Eargle



The Rare Disease Champion Award is presented annually by Uplifting Athletes to a leader in the world of college football who has realized his or her potential to make a positive and lasting impact on the rare disease community.

In 2019 we honored former Austin Peay State University Offensive Coordinator and current University of Kansas Assistant Coach Joshua Eargle as the 11th winner of the Rare Disease Champion Award.

Coach Eargle's daughter Landrey is the first known case in the United States to be diagnosed with the condition of a rare gene mutation of the CSNK2B gene. His calm under extreme pressure allows their family to have a laser focus on their mission: to impact people through faith, to demonstrate joy through adversity and to medically document the future of the rare gene mutation their daughter battles.

Past Champion Spotlight: Jake Olson



Since winning the 2016 Uplifting Athletes Rare Disease Champion Award Jake Olson has continued to amaze everyone with his ability to defy the odds and accomplish whatever he sets his mind to. During the 2018 season Jake saw live action as a short snapper for the USC Trojans in their game against Western Michigan. After his senior season Jake participated in the USC Pro Day in front of dozens of NFL Scouts. In typical Jake fashion, he used his platform to help raise money in support of Retinoblastoma research and Uplifting Athletes. In the spring, Jake continued his support of a promising treatment for Retinoblastoma through his Out Of Sight Faith Foundation by partnering with Uplifting Athletes to fund the Collaborative Leadership Grant awarded to Dr. Brenda Gallie during the 2019 Young Investigator Draft.



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 2019, 37 college football student-athlete leaders from 19 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 is an incredible opportunity for us to use our platform as college athletes to raise awareness for a great cause. It is very special for our program to be able to work with an organization that can make an impact in the fight against rare diseases."

Brock Wright, Notre Dame Chapter Vice President & Tight End



LIFT FOR LIFE & TOUCHDOWN PLEDGE DRIVE

Lift for Life is our signature fundraising event. This event empowers student-athletes to turn a workout into an event to raise money and awareness for the Rare Disease Community.

21 Chapters
raised
\$175,321

Touchdown Pledge Drive is a student-athlete led initiative to shine a national spotlight on rare diseases during the time of year teams are most relevant - during the college football season.

15 Chapters
raised
\$25,517

Each chapter embraces the mission of Uplifting Athletes by using college football as a platform to inspire the Rare Disease Community with hope through the power of sport.



"Lift for Life and Uplifting Athletes has broadened our sense of purpose beyond football here at Western. We realize that we have an opportunity to be a voice for those who do not have one. Our program is thankful to have a small part in inspiring hope within the Rare Disease Community"

Justin Tranquill, Western Michigan Chapter President & Safety



UPLIFTING AMBASSADORS

For the fifth 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.

\$44,768

Amount raised by the 54 NFL prospects who participated in the 2019 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. In 2019 that included **Malik Turner**, Jake Olson, Riley Dixon, Cameron Lynch, Zaire Franklin, Garry Gilliam and Ryan Bates.





UPLIFTING EXPERIENCES

The focus and purpose of Uplifting Experiences is to share the spotlight afforded to athletes with rare disease patients, families and caregivers. This includes the annual Notre Dame Chapter Bowling Event and Rare Disease Awareness Games that involved the Syracuse, Western Michigan, Princeton and Penn Chapters.

More than 100 people packed the lanes for two hours of fun and inspiration at the 2019 Notre Dame Bowling Event including more than 70 patients, siblings and caregivers along with 30 Fighting Irish football players from the Notre Dame Chapter.



"Sometimes these kids look up to us and wish they were in our shoes. We are grateful to get to spend some time with them, their friends and family, and give back to the Rare Disease Community."

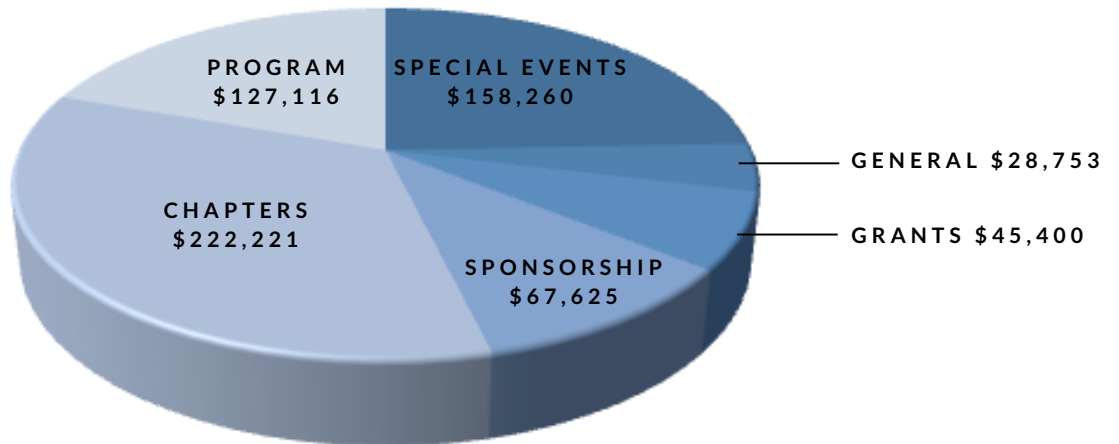
Drew White, Notre Dame Chapter Vice President & Linebacker





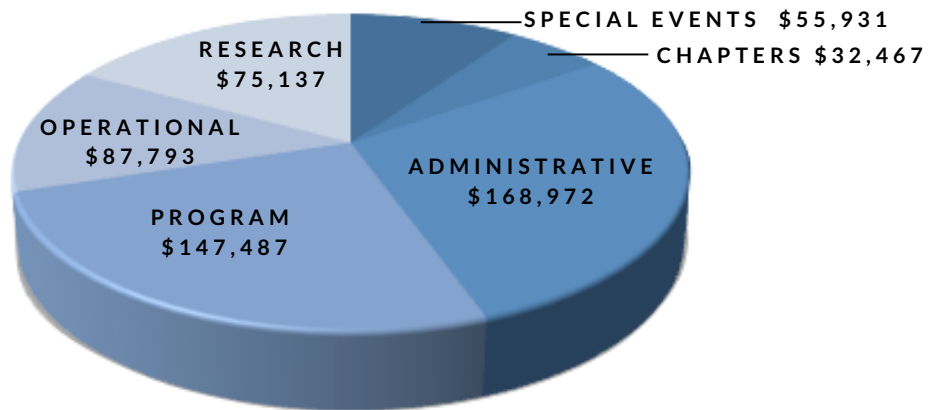
FY 2018 - Financial Report

Fiscal Year 2018 - Revenue



Total: \$649,428

Fiscal Year 2018 - Expenses



Total: \$577,787

UPLIFTING STAFF



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BOARD



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Vice President



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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.



#WETACKLE RARE

