



**CREATING A BRIGHTER FUTURE**  
*for individuals and families impacted by rare disease*





Dear Uplifting Athletes Community,

I am humbled and inspired by your commitment and support throughout the year. It is with great pride and optimism that I reflect on our collective journey and envision the future we are building together.

We are more than just a rare disease organization; we are a community united by a common purpose – leveraging the power of sport to invest in the lives of those facing the challenges of rare diseases.

In 2023, we made significant strides in expanding opportunities for the rare disease community and driving research forward. With the announcement of the Researcher Connection Program, we focused on bringing together researchers with the patient and caregiver community they serve so that researchers can better understand how to focus their research efforts. Additionally, our relaunched Uplifting Experiences program has exceeded expectations. We have provided 25 experiences to more than 300 individuals impacted by a rare diagnosis, and we are just getting started.

The Young Investigator Draft continued to thrive, funding ten brilliant researchers with \$200,000. This investment is not just financial backing; it's an investment in the hope and future of countless individuals and their families.

Our success is your success, and our impact is your impact. We couldn't achieve all that we do without your support. Your generosity, dedication, and passion have made a genuine difference in the lives of those we serve.

As we look ahead, we are filled with excitement and anticipation for the opportunities that await us. Our commitment to creating a brighter future remains unwavering, and with your support, we will continue to drive meaningful change as we look to sustain and enhance our current programming.

Thank you for your continued dedication, and I am honored to continue this journey with each and every one of you. Our mission is powerful, and it is only through our shared effort that we can truly make a difference.

Sincerely,

Rob Long, Uplifting Athletes, Executive Director



## OUR MISSION

Harness the power of sport to build a community that invests in the lives of people impacted by rare diseases.

## OUR VISION

No person impacted by a rare disease feels alone and everyone is inspired with hope for the future.

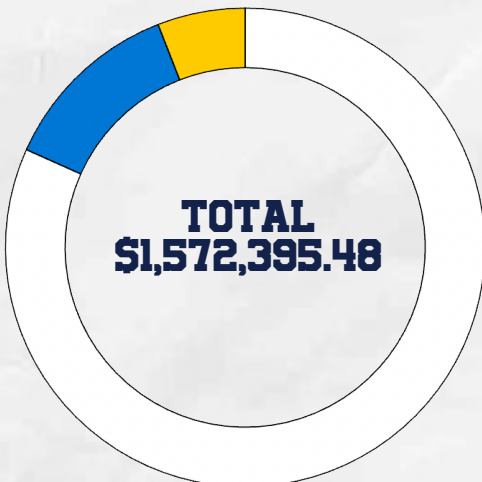
## OUR HISTORY

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 one, Uplifting Athletes focused on using the platform of college athletics 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 their respective playing fields.

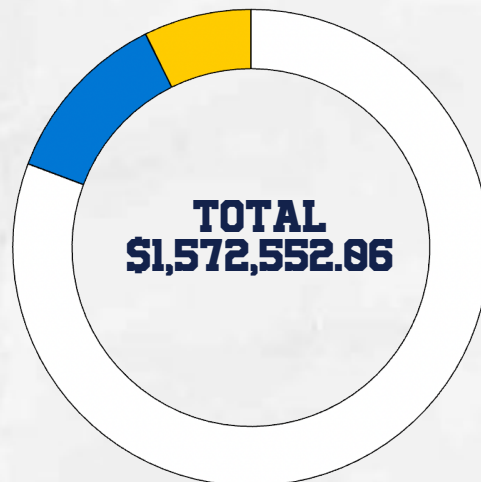
All the annual events and fundraisers associated with Uplifting Athletes fuel our commitment to create Uplifting Leaders, engage in Uplifting Experiences, fund rare disease research, and expand rare disease awareness.

## 2023 REVENUE



**PROGRAM -**  
**\$1,282,971.82**  
**CHAPTERS -**  
**\$196,406.52**  
**GENERAL -**  
**\$93,017.14**

## 2023 EXPENSES



**PROGRAM -**  
**\$1,269,389.34**  
**ADMINISTRATIVE**  
**- \$188,363.11**  
**FUNDRAISING -**  
**\$114,799.61**



# 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.

Including this year, Uplifting Athletes has provided more than \$820,000 in funding to rare disease researchers. 2023 was the first year Uplifting Athletes funded ten researchers with grants.

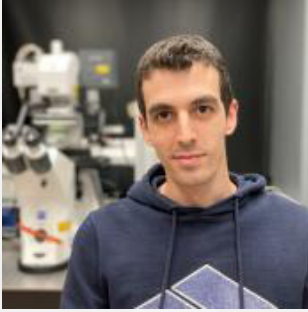
## UNDERREPRESENTED RESEARCHERS IN MEDICINE INITIATIVE

To promote diversity, equity, and inclusion in medicine and medical research, the URM initiative leverages the mechanism of the Young Investigator Draft to fund and celebrate researchers from underrepresented backgrounds.



**“THE UPLIFTING ATHLETES YOUNG INVESTIGATOR DRAFT WAS AN INCREDIBLE EVENT THAT TRULY SHOWCASED THE ENERGY AND PASSION OF RARE DISEASE RESEARCH...AS AN EARLY CAREER SCIENTIST, THIS AWARD IS ESPECIALLY MEANINGFUL TO ME, AS IT HAS ALLOWED ME TO LAUNCH MY RESEARCH LAB. I AM GRATEFUL TO UPLIFTING ATHLETES FOR THEIR UNWAVERING SUPPORT OF RARE DISEASE RESEARCH!” DR. KELLY CROWE**

# 2023 DRAFT CLASS



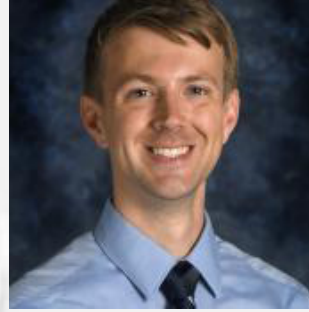
**DR. ALEX FELIX**

University of Pennsylvania  
Nominated by: STXBPI Foundation



**DR. ANNA STEPANOVA**

Brain and Mind Research Institute, Weill  
Cornell Medical College  
Nominated by: The Friedrich's Ataxia  
Research Alliance



**DR. CHRISTOPHER SANDE**

University of Pennsylvania  
Nominated by: Team Telomere



**DR. JITHMA PRASAD ABEYKOON**

Mayo Clinic, MN  
Nominated by: ECD Global Alliance



**DR. KELLY CROWE**

Xavier University  
Nominated by: Neuromuscular Disease  
Foundation



**DR. MELANIE MUMAU**

University of Pennsylvania  
Nominated by: Castelman Disease  
Collaborative Network



**DR. NISHANTHI MATHIYALAGAN**

Brigham and Women's Hospital/  
Harvard Medical School  
Nominated by: TANGO2 Research  
Foundation



**DR. RILEY E. PERSZYK**

Emory University  
Nominated by: GRIN2B Foundation



**DR. STEVEN BAKER**

University of Utah  
Nominated by: Association for Creatine  
Deficiencies



**DR. ZAIN AWAMLEH**

The Hospital for Sick Children  
Nominated by: TBRs Community



# 2022 RARE DISEASE CHAMPION TEAM



For 14 years, Uplifting Athletes has celebrated leaders in college athletics that have made a positive and lasting impact on the rare disease community. 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.

The 2022 team consisted of Aristotle Thompson (University of California, Berkley), JD Bertrand (University of Notre Dame), Jenny Cape (University of Iowa), and Tylee Craft (University of North Carolina).

## REPS FOR RARE DISEASES

For the ninth 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. With 54 NFL participating athletes during the 2023 Reps for Rare Diseases campaign, nearly \$20,000 was raised to create an exceptional impact.

## UPLIFTING AMBASSADORS

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.

During the 2022 NFL season, four Uplifting Ambassadors supported the rare disease community through My Cause My Cleats: Montrell Washington (Denver Broncos), Riley Dixon (Los Angeles Rams), Clay Johnston (Cincinnati Bengals), and Nick Allegretti (Kansas City Chiefs).



# LIFT FOR LIFE

Lift For Life is the signature fundraising event for each Uplifting Athletes chapter with student-athletes organizing and executing their perspective campaigns. In 2023, Uplifting Athletes schools raised over \$168,000 from 30 events held across the country. Lift for Life expanded to include four sports: football, women's volleyball, women's soccer, and women's field hockey and in 2023 Uplifting Athletes invited eight new teams to hold their own Lift for Life events!



**“THE MOST REWARDING PART OF PARTICIPATING IN LIFT FOR LIFE IS KNOWING THAT WHAT I AM DOING IS MAKING A DIFFERENCE IN OTHERS’ LIVES. IT’S CRUCIAL WE USE THE VOICE AND PLATFORM WE ARE GIVEN THROUGH ATHLETICS TO SUPPORT OTHERS.”** **ABBIE BROWN,**  
**FIELD HOCKEY, LEHIGH UNIVERSITY**

# UPLIFTING LEADERS



The catalyst for the Uplifting Leaders program is the annual Leadership Development Conference. Leaders from each current and prospective chapter attend this conference to focus on the development of transferable life skills, rare disease advocacy, and leadership.

This is a unique education initiative for student-athletes to learn to maximize their platform on their campus to raise awareness on behalf of the rare disease community.

In 2023, 58 student-athletes from chapters and prospect chapter universities attended the conference in Philadelphia.



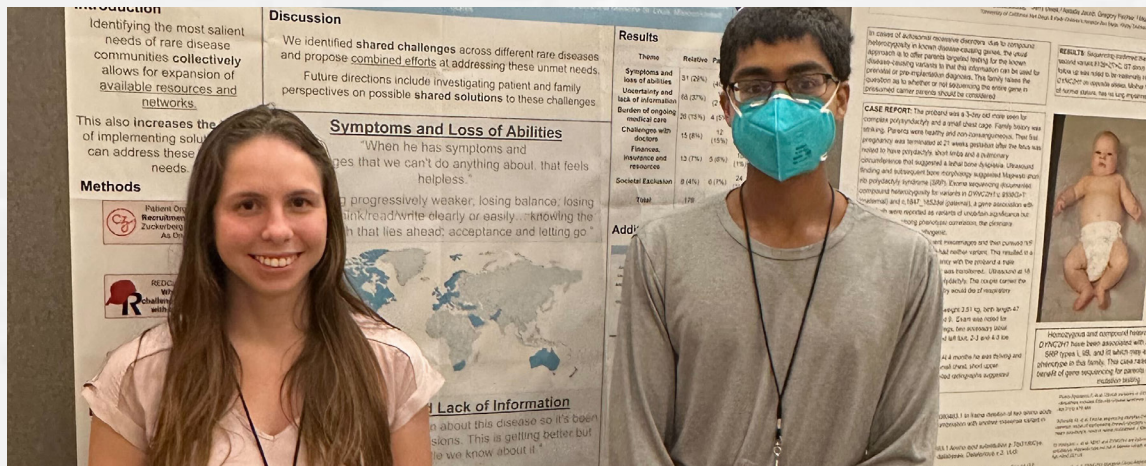
# TOUCHDOWN PLEDGE DRIVES

During the 2022-2023 college football season, several chapters dedicated their games to support of the Uplifting Athletes mission by holding a Touchdown Pledge Drive. A total of 14 chapters participated in Touchdown Pledge Drive, and \$15,391 was raised to support the rare disease community.

# RESEARCHER CONNECTION PROGRAM

The Researcher Connection Program assists with travel expenses for researchers and professional students interested in the rare disease field. This funding provides opportunities for these individuals to connect in-person with those directly impacted by their research to foster collaboration and communication.

Within its first year, the Research Connection Program was able to support participants with a wide variety of focus areas which included: lysosomal storage diseases, CHD2 haploinsufficiency, mitochondrial dysfunction in adrenoleukodystrophy (ALD), Gorlin syndrome, Fibrous Dysplasia/ McCune-Albright, rare genetic syndromes, congenital morphogenic diseases, tuberous sclerosis complex (TSC), early infantile epileptic encephalopathy type 25 (SLC13A5 epilepsy), and DDX3X syndrome. Uplifting Athletes was able to provide \$13,547 of funds to 11 researchers.



**“THE BURDEN OF HAVING TO EXPLAIN, TO BE AN EXPERT, AND TO EDUCATE FALLS ON MANY RARE DISEASE PATIENTS AND FAMILIES. THIS WAS A NECESSARY REMINDER THAT AS A FUTURE CLINICIAN, THERE ARE BURDENS I CAN DO MY BEST TO ADDRESS. WE SHOULD RESPECTFULLY LEARN FROM PATIENTS, AMPLIFYING THEIR VOICES, WHILE ALSO ACKNOWLEDGING THAT MANY WAYS IN WHICH WE CAN CONTRIBUTE TO MAKING BROADER SOCIETAL CHANGES.” ELIZABETH GONZALEZ**

\*Uplifting Athletes' Researcher Connection Program launched in Spring 2023 as the Researcher Travel Program.



# 10,000 MILE CHALLENGE

The rare disease community is a diverse ecosystem of individuals who, together, are stronger when we work together. Through the Uplifting Athletes 10,000 Mile Challenge presented by Sanofi, people from all walks of life are invited to measure their steps to help reach our 10,000 mile collective goal and our ultimate fundraising goal. With 32 teams and 503 participants, we were able to raise \$59,575 and log 19,822 miles far surpassing our original goal!



# UPLIFTING EXPERIENCES

To create a brighter future where no person affected by rare diseases feels alone, Uplifting Athletes offers Uplifting Experiences as an opportunity to harness the power of sport to bring communities together. An Uplifting Experience connects people of all ages impacted by rare disease with an athlete, team, or sports organization for a unique and memorable experience at no cost to participants.

Throughout the year, Uplifting Athletes hosted 295 participants at 26 events across the country.

Uplifting Athletes partnered with 17 different professional and collegiate sports teams for Uplifting Experiences. 100% of attendees surveyed felt their experience had a positive impact on them and their family members!



**“IN A COMMUNITY OF PARENTS DEALING WITH KIDS WITH DISABILITIES OR MEDICAL DISORDERS, THERE ARE TIMES WHEN WE ARE MADE TO FEEL DIFFERENT AND ISOLATED. EVENTS LIKE THESE SHOW THAT OUR KIDS ARE NO DIFFERENT THAN KIDS WITHOUT DISABILITIES. THEY ALL JUST WANT TO LAUGH, PLAY, MAKE NEW FRIENDS AND HAVE A GOOD TIME.” FELICIA, RARE GRANDPARENT**

# A SPECIAL THANK YOU TO OUR 2023 PARTNERS

## SPONSORS



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