STRIDING FORWARD

SKDEAS 2023 Annual Report

A MESSAGE FROM

KYLE HILLMAN

Vice-President & Treasurer, Parent of Rowen

Dear SKDEAS Community and Supporters,

In the brief time since our foundation's inception in July 2022, inspired by a group of devoted parents, we have seen extraordinary growth and impact. Our journey, driven by the desire to advance scientific research and provide comprehensive support to families affected by Skraban-Deardorff Syndrome, has been both challenging and rewarding.

As we look back on our journey we are filled with heartfelt appreciation for each one of you. Your support, in all of its forms, has been the bedrock upon which our nonprofit has grown and flourished. This past year has been a remarkable testament to the power of community and collective effort. Your contributions, whether through donations, volunteering, or spreading our message, have been instrumental in bringing our mission to life.

The core of our organization has always been the community we serve. The stories of hope, the smiles of our superheroes, and the sense of togetherness we've fostered are daily reminders of the impact of our collective actions. Your belief in our mission has not only propelled us forward but has also ignited hope and positive change in countless lives.

This annual report is more than a summary of what we have accomplished; it is a narrative of growth, community, and shared dreams. Looking ahead, we are excited about the potential that your ongoing support holds. Your partnership is crucial in helping us continue to make meaningful differences in the lives of those we serve.

On behalf of our team and the families we work with, we extend our deepest thanks. Your engagement with our cause is more than just a contribution; it is the foundation of a strong and lasting partnership. We eagerly anticipate what we will achieve together in the years to come.

With heartfelt thanks,

Skraban-Deardorff Syndrome Foundation

MISSION STATEMENT

The Skraban-Deardorff Syndrome Foundation has been formed by parents and medical professionals worldwide to foster relationships and organize resources to benefit individuals with Skraban-Deardorff Syndrome. Our goal is to raise funds for research, promote public awareness, and align scientists, patients, parents, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to treating people with Skraban-Deardorff Syndrome and related diseases.

YEAR IN REVIEW

2023

TOWN HALL MEETING

We hosted our inaugural Town Hall Meeting, which marked a significant milestone for our community. With over 25 families participating, the event, led by Dr. Skraban and Dr. Deardorff, provided an interactive platform for in-depth discussions on vital topics such as Neurodevelopment Assessment, Research & Funding, Gene Therapy, Genetic Questions, Hearing Loss, Verbal Acquisition, Developmental Delays, and WDR26 Diagnostic Codes. The meeting fostered strong connections between healthcare professionals, patients, and families, deepening our understanding of various aspects of care. The session concluded on a high note with a lively Dance Party, adding a touch of joy and celebration to the informative event.

REGISTRATION FORM

The SKDEAS Foundation successfully launched a Parent/Child Registration initiative, building a robust global community to support those diagnosed with WDR26 and their families. This effort was instrumental in gathering current data about each family within the SKDEAS community, enhancing our understanding and ability to provide targeted support. This initiative has been a vital step in strengthening our network and deepening our insight into the needs of our community members.

BIRTHDAY CLUB COMMITTEE

We launched the "Birthday Club Committee," a vibrant initiative aimed at enriching our organization's community spirit. This committee is designed to organizing and executing birthday celebrations for our members, creating a warm, inclusive atmosphere.

IMPLEMENTATION OF CRM & DONOR MANAGEMENT PLATFORMS

Our strategic implementation of Kindful, a leading Nonprofit CRM platform, was born out of extensive research and comparison of various options. Kindful, selected for its comprehensive tools in donor management, volunteer coordination, and online fundraising, enhances our operational efficiency. It offers robust features in email marketing, reporting, and analytics, vital for fostering stronger relationships with our supporters and ensuring optimal use of every contribution. This decision reflects our commitment to utilizing advanced technology for effective management and directing resources toward impactful support and research for families affected by WDR26 diagnoses.

PODCAST TRANSCRIPTION

We embarked on an initiative to enhance the accessibility of our podcast content by transcribing episodes. This endeavor was aimed at ensuring that our diverse audience, regardless of their preferred mode of content consumption or native language, could access and engage with the valuable insights and stories shared in our podcasts. By offering transcriptions, we broadened the scope of our audience, fostering greater inclusivity and engagement, and enriching the community experience with our content.

NATIONAL ORGANIZATION FOR RARE DISORDERS

[1] NORD Registry Inclusion: In August 2023, the SKDEAS Foundation achieved a major milestone with the inclusion of Skraban-Deardorff syndrome in the National Organization for Rare Disorders (NORD) registry. This inclusion represents a crucial step in raising awareness and understanding of the syndrome within the medical and research communities.

[2] WDR26-Related Disorder Report: NORD has gratefully acknowledged Dr. Cara Skraban and the Skraban-Deardorff Syndrome Foundation for their instrumental role in preparing a detailed report on Skraban-Deardorff syndrome. This recognition underscores the foundation's dedication to advancing research and knowledge about the condition.

[3] Platinum Membership with NORD: The SKDEAS Foundation has been honored with Platinum membership status by NORD, the highest and most prestigious level of membership. This distinction highlights the foundation's significant contributions and commitment to the rare disease community, positioning it as a leading advocate and resource in the field.

[4] RareAction Network: The RareAction Network, powered by the National Organization for Rare Disorders (NORD), serves to connect and empower a unified network of individuals and organizations with tools, training and resources to become effective advocates for rare diseases through national and state based initiatives across the United States. We stand for equitable access to timely diagnosis, treatment and care for every person impacted by a rare disease.

SMILE OF THE MONTH

The "Smile of the Month" initiative by the SKDEAS Foundation aims to foster a strong sense of community among SKDEAS families and connect personally with our global audience. Each month, we feature a "SKDEAS Smile," celebrating the unique stories and experiences within our community. We encourage our families to share their stories and information they would like to be considered for a future feature. This endeavor not only highlights individual journeys but also brings us closer together, sharing in the joy and resilience of our community.

FUNDRAISING EVENTS

This past year, the SKDEAS Foundation celebrated two significant fundraising events: a series of wine tasting parties and a golf outing. These events not only served as vital fundraising opportunities but also as enjoyable social gatherings that brought our community together. The wine tasting parties offered a sophisticated and enjoyable way for supporters to engage with our cause, while the golf outing provided a day of leisure and networking, all in support of the Foundation's mission. Both events were successful in raising awareness and funds, contributing significantly to our ongoing efforts.

CANDID'S GOLD SEAL OF TRANSPARENCY

The Skraban-Deardorff Syndrome Foundation proudly earned Candid's Gold Seal of Transparency, a prestigious recognition awarded to less than 20% of nonprofits for exceptional openness and accountability. This achievement highlights our dedication to providing transparent and accessible information to our stakeholders and reinforces our commitment to fostering a transparent and equitable nonprofit sector. We're excited to continue our work with this esteemed distinction, reflecting our commitment to integrity and transparency in all our endeavors.

RESEARCH STUDY

We've surpassed our fundraising goal for the pioneering neurodevelopmental assessment project for Skraban-Deardorff Syndrome. This success enables crucial research into cognitive and behavioral development, essential for understanding and improving treatment strategies. We're collaborating with Dr. Thomas Frazier of John Carroll University, a notable ASD researcher, to implement innovative assessment methods. This achievement, bolstered by your generosity, emboldens our optimism and commitment to impactful research within the SKDEAS community.

GIVING TUESDAY DONOR MATCH

An anonymous donor generously agreed to match funds for our Giving Tuesday campaign, a global initiative encouraging people to donate to charitable causes following Thanksgiving. This remarkable gesture significantly amplified our fundraising efforts, leading us to exceed our set goal. The success of this campaign, fueled by the matching donation and the incredible support from our community, has been a major boost to our initiatives and will have a lasting impact on our work.

PARTNERSHIP AND MEMBER ORGANIZATIONS

The SKDEAS Foundation has proudly expanded its reach and impact by joining forces with various member organizations and establishing key partnerships. This strategic move not only signifies our commitment to broadening our network but also enhances our ability to collaborate, share resources, and gain new insights. These alliances are pivotal in furthering our mission and amplifying our efforts to support and advocate for those affected by Skraban-Deardorff Syndrome. Each partnership brings unique strengths and opportunities.

RARE DISEASE INTERNATIONAL

Rare Diseases International (RDI), an alliance of over 90 member organizations from 46 countries, advocates globally for rare disease patients. SKDEAS Foundation's partnership with RDI expands our reach and enhances our impact, leveraging combined resources and expertise. This collaboration fosters innovation and stronger advocacy for individuals with Skraban-Deardorff Syndrome, connecting us to a broader community and enabling shared progress in our mission.

EPILEPSY FOUNDATION

The mission of the Epilepsy Foundation is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. For more than five decades, the Epilepsy Foundation and our network of nearly 50 partners have helped to:

- Connect people to treatment, support and resources;
- Fund innovative research and the training of specialists; and
- Educate the public about epilepsy and seizure first aid.

UNITED WAY OF CENTRAL INDIANA

The SKDEAS Foundation has formed a partnership with the United Way of Central Indiana to facilitate payroll deduction and donation earmarking. This collaboration allows employees in the region to easily contribute to the foundation through their payroll, providing a seamless and convenient way to support our cause. This initiative not only simplifies the donation process but also opens up a new avenue for sustained support, helping us further our mission in supporting individuals with Skraban-Deardorff Syndrome and their families.

NORTH CAROLINA CENTER FOR NONPROFITS

The SKDEAS Foundation's association with the North Carolina Center for Nonprofits, founded by Jane Kendall in 1990 to bolster nonprofit collaboration, aligns with our objectives of organizational strengthening and sector enhancement. This partnership offers us invaluable insights from a wide network of leaders across various sectors, ensuring that we remain adaptable and responsive to the evolving needs of the nonprofit landscape. Engaging with this center enables us to refine our strategies and continue making impactful strides in supporting the Skraban-Deardorff Syndrome community.

FINANCIAL OVERVIEW

2023

2022 FUNDS RAISED

$46,648.89

Total Donors - 232

Average Donation - $201.07

2022 EXPENDITURES

$1,444.91

State and Federal Filings, startup expenses

2023 FUNDS RAISED

$73,137.87

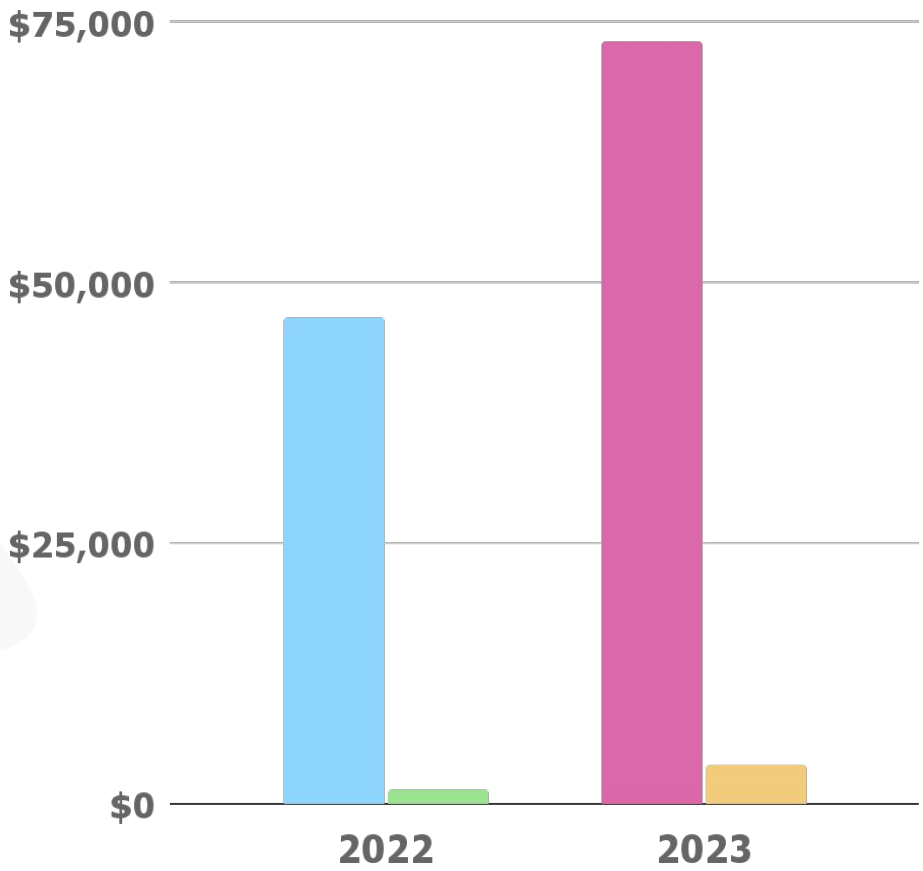
Total Donors - 312

Average Donation - $234.42

2023 EXPENDITURES

$3,678.77

Banking, mailing supplies, CRM platform, email marketing, technology



DONOR ACKNOWLEDGEMENT

Our Heartfelt Thanks to Our Donors:

We are immensely grateful to each individual and organization whose generosity has fueled our mission. Below is a list of donors who have played a pivotal role in our journey. While we strive for accuracy in our records, please accept our apologies for any misspellings or omissions, particularly for those who donated through social media, as our donation platform may not be fully synced with these channels. If you notice any discrepancies, kindly let us know so we can correct our records.

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MEDICAL SPOTLIGHTS

2023

DR CARA SKRABAN, MD

I am a clinical geneticist at the Children's Hospital of Philadelphia and Associate Professor of Clinical Pediatrics at the Perelman School of Medicine at the University of Pennsylvania. I am a full-time clinician which means I get to spend most of my days working with patients and families, teaching, and training the next generation of clinical geneticists. I am originally from South Florida and completed my undergraduate degree at Rollins College. I then went to medical school at the University of Virginia where I also did my residency training in Pediatrics. Following residency, I came to Philadelphia for my medical genetics training at the Children's Hospital of Philadelphia (CHOP) where I have since remained.

As part of my genetics training at CHOP, I was fortunate enough to conduct research in the laboratory of Dr. Matt Deardorff. During that time, we stumbled onto a patient with a change in the gene WDR26 that eventually brought us to the initial description of the condition, now known as Skraban-Deardorff syndrome, in 2017. Since that time, I have had the pleasure of continuing to work with these amazing individuals. They are truly awe-inspiring. Their resilience, infectious energy, and pure joy for life makes it easy to instantly fall in love with them and motivates me to want to continue striving to find ways to improve their lives. All it takes is to see them smile and you're hooked. Their families are the most dedicated and motivated group of people that I have ever had the privilege with which to work, and it is no secret that they are the force behind the success of the Skraban-Deardorff Syndrome Foundation. Without them, none of this would be possible. Sincere thank you to them for everything they do and for the honor of being part of their children's lives.

DR MATT DEARDORFF, MD

I am a clinical geneticist and physician-scientist and serve as the Director of Personalized Care at the Children's Hospital Los Angeles as well as a Professor of Clinical Pathology and Pediatrics at the Keck School of Medicine of the University of Southern California. In a nutshell, I spend my time trying to figure out how to more quickly diagnose children with genetic disorders and figure out the best ways to help them.

I grew up on a farm in Central Pennsylvania, and after attending Bucknell University, spent nearly 30 years in Philadelphia. This started at the University of Pennsylvania (Penn) doing my medical degree and a PhD in molecular and developmental biology. I then shifted to Children's Hospital of Philadelphia (CHOP) for my residencies in Pediatrics and Clinical Genetics. Following that, I got my "first real job" (according to my late father) at CHOP and Penn seeing children with rare disorders in clinic and working to better understand their cause in my research lab. As with many of the important projects in my lab, our introduction to WDR26 came from a seeing a young girl in clinic. At that time, we knew very little about the WDR26 gene and even less about what the clinical effects of changes in the gene might be. This encounter, now more than 10years ago, has developed into a much, much broader effort with dozens of families and a growing list of scientific collaborators. However, the encounters with every individual child, as well as the inspiration from families when they get together, have served to push us to ask the hard, but critical questions that will hopefully one day lead us to better treatments.

In 2020, I was recruited to come to Children's Hospital Los Angeles to identify ways to diagnose and propose therapies for children at a health system-wide level. To help me with this, I have had the good fortune of many amazing meaningful encounters with families and family support foundations. These experiences serve as a constant anchor when trying to navigate change in a large health system for children with rare disorders!

KATIE GRAND, MS, CGC

My name is Katie Grand and I am a genetic counselor in the Department of Pediatrics at Cedars-Sinai Medical Center Los Angeles, California. I was born and raised in Harrison Township, Michigan, which is a suburb of Detroit, and did my undergraduate education at the University of Michigan (go blue!). After undergrad, I attended Arcadia University and graduated with my Masters of Science in Genetic Counseling. Prior to moving to Los Angeles, I worked at the Children's Hospital of Philadelphia with Matt Deardorff and Cara Skraban where I was lucky enough to start working with the SKDEAS population. It has been surreal to compare when we first started this journey to now. My favorite part of working with the SKDEAS population is by far interacting with the kids and their families. The kids are some of the most joyous, loving, and inspiring kids that I have ever met and their parents are supporting them in every way. When I am not working, I enjoy walking with my dog, Darla, traveling, and being outside.

CHRISTOPHER GRAY, MS, LCGC

My name is Christopher Gray, and I have been a clinical genetic counselor in the Division of Human Genetics at Children's Hospital of Philadelphia (CHOP) since 2018. I work on a team of very talented geneticists and genetic counselors to evaluate patients who are referred to our clinics for various reasons, though I am particularly fortunate enough to be able to work along with Dr. Skraban in the evaluation and management of our SKDEAS population here at CHOP. I have also developed close relationships with Dr. Deardorff and Katie Grand who have since transitioned from CHOP to new roles in Los Angeles, California. When I am not seeing patients, I enjoy contributing to the work of the SKDEAS Foundation alongside an amazing team of impassioned families, clinicians, and scientists, all working together expand our understanding of this diagnosis and connect our growing global community.

I originally grew up in Brampton, which is a city located just outside of Toronto, Ontario, Canada. I obtained my Bachelor of Science degree in Biology and Molecular Genetics from Queen's University in Kingston, Ontario, before going on to complete my Master of Science degree in Genetic Counseling from the University of Toronto. I come from a long lineage of nurses and teachers in my family, so when I learned that I could combine my love for genetics, medicine, education, and psychosocial counseling into one career, I knew that genetic counseling was the right path for me. During my clinical training at the Hospital for Sick Children in Toronto, I grew a particular affinity for working with undiagnosed and rare diagnosis populations. The tenacity of these young children and the motivation of their parents/guardians left a profound impact on me, and informed my decision to begin my career here at CHOP.

I am also struck by the generous nature of SKDEAS parents, parent figures, and guardians. Whenever we make a new diagnosis, or see a newly diagnosed patient for the first time, we are almost always asked, "how can we get involved? How can we help?". It is this generosity that has allowed us to learn so much about this diagnosis in such a short amount of time, and is something that I never take for granted.

And who can say anything about SKDEAS without mentioning the smiles, which to me are a beacon of aspiration – a reminder to always have a gentle heart and a positive spirit. Your children and families motivate me every day, and I thank you for entrusting me with the privilege of being involved in the care of your children and your wonderful community.

CLOSING

As we conclude this year's annual report, we look back on a year filled with significant achievements and the steadfast support of our community. This report not only highlights the strides we've made but also reinforces our dedication to the mission that guides the SKDEAS Foundation. We express our sincere gratitude to all who have journeyed with us. Your ongoing support and belief in our cause fuel our continued progress and optimism for the future. Here's to another year of impactful work and moving closer towards our collective goals.

Skraban-Deardorff Syndrome Foundation

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2023