A Cure for Sophia and Friends
2023/24 Fiscal Year Report

A Rare Village Foundation Fund

"A Cure for Sophia and Friends paves the way towards a cure for the ultra-rare RARB genetic mutation (MCOPS12). A Cure for Sophia and Friends is the U.S. based non-profit in partnership with Cure MCOPS12, a non-profit based in Austria. Together, we accelerate cutting-edge research and drive relentless efforts to improve the lives of MCOPS12 patients."

June 30, 2024

Dear MCOPS12 supporters,

As A Cure for Sophia and Friends ends its first fiscal year, we are thrilled to announce that thanks to your personal generosity and a grant for $24K from Capital Cares of Capital Group, we have not only met our goal of $50K for our drug repurposing, but we have raised just over $70K as of June 30, 2024.

Thanks to our wonderful partnership with Rare Village Foundation, we were able to begin fundraising for our research initiatives in October 2023 just in time for Giving Day! Without Rare Village's fiscal sponsorship, we would not have been able to begin fundraising as a non-profit and receive the grants we have. Thank you Rare Village!

As we developed the Cure for Sophia and Friends Executive Board, I was thrilled to have one of my dear friends from high school join our cause. When I first spoke about putting together a foundation many years ago to support Sophia and others with MCOPS12 Syndrome, Rischel was at the front of the line to let me know that she'd like to help and further our cause with the assistance her corporation, Capital Group, could provide. I never could have imagined the magnitude that her participation along with Capital Group could provide for our organization. Not only has Rischel been hard at work to share our mission as a volunteer and allowed us to receive our large grant from the Capital Cares division of Capital Group, but she orchestrated a company wide presentation that reached out to over 500 associates for additional volunteer support and education on the mission of A Cure for Sophia and Friends. Thank you Rischel!

Regarding our drug repurposing study, Everlum Bio has started initial experiments, such as development of a readout for the drug. However, in order to begin testing these compounds, they require a viable cell model. Unfortunately, the cell model that was being generated prior to the drug repurposing study is not viable, and we need to begin the process of creating another one to complete the study.

While we work on confirming the best choice to generate the new cell model, A Cure for Sophia and Friends has been able to assist one of our worldwide partners, Cure MCOPS12, with funding for our biomarker study. Biomarkers are imperative to further study as they are utilized to show disease progression and are typically a requirement before beginning a clinical trial which would be the next step after our drug repurposing study is complete.

As we look to our next fiscal year, we are planning to fund our new cell model, complete the biomarker study and hopefully provide some travel grants for our first in-person MCOPS12 patient symposium/conference in Montreal, Canada in the summer of 2025 with our researchers at CHU Sainte-Justine!

As Executive Director of A Cure for Sophia and Friends, I am humbled by the outpouring of generosity and support we have received in our first year. I know with your continued support we can make a difference for our MCOPS12 families. I look forward to sharing our year-end report with you once it is available to see exactly how your donations have been utilized to fund this potentially life-changing research for our MCOPS12 families!

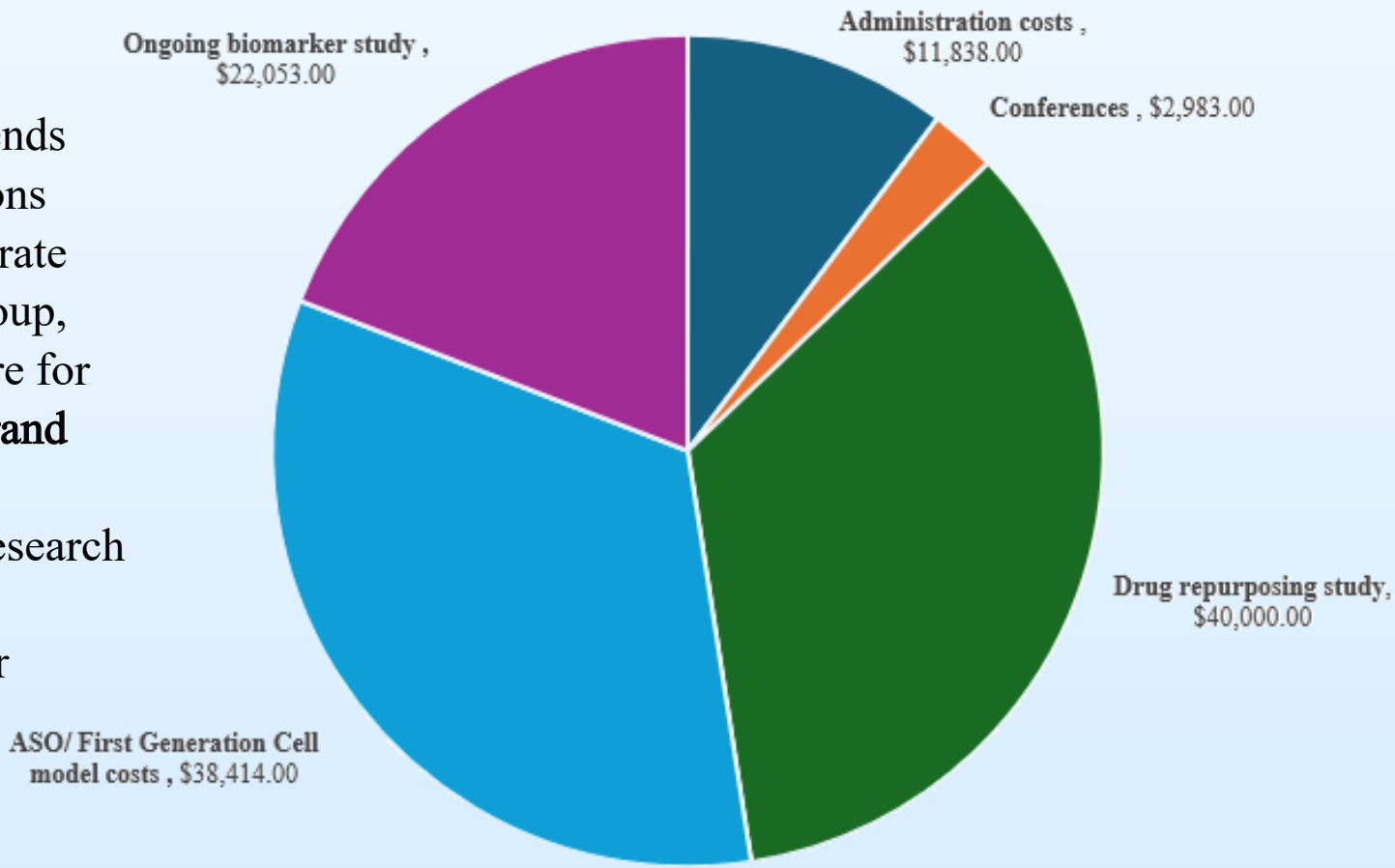
With humble gratitude,

Rachel Sutherland

Executive Director, A Cure for Sophia and Friends and Mom to one amazing girl!

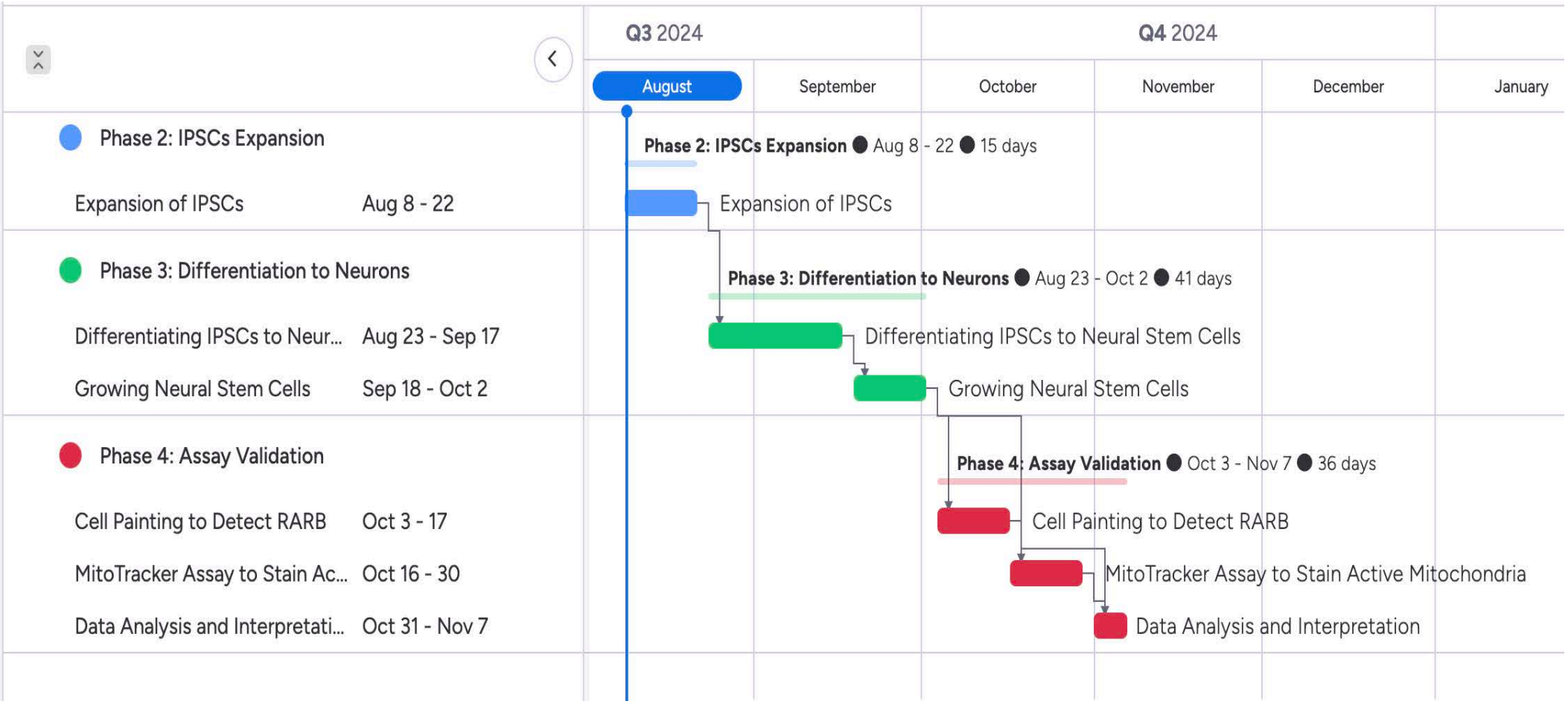
2023/24 Financials

Thanks to your generosity, A Cure for Sophia and Friends received individual donations totaling $57,080 and corporate donations from Capital Group, Cure MCOPS12 and A Cure for Sienna for $60,560 for a **grand total of $117,640!**
These donations covered research projects, conferences and administration costs for our inaugural year.



Final Stages of our Drug Repurposing Study

We are well on our way to completing our drug repurposing study as indicated below.
(Pending timely delivery of viable stem cells)



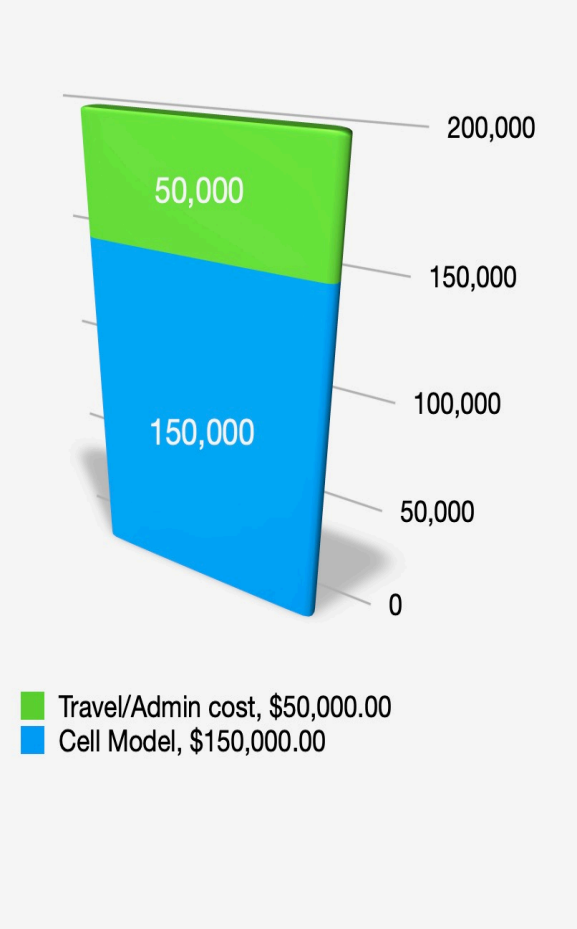
2024/25 Goals

- Finalize results for our drug repurposing study

- Generating a second cell model to effectively test the Antisense Oligonucleotide (ASO) and complete our drug repurposing study

- Complete our biomarker study to help us move into clinical trials for drug compounds once the drug repurposing study is complete

- Plan a symposium/ conference with travel grants to bring together as many patient families as possible with MCOPS12 syndrome in the summer of 2025



We are so thankful for our partners in their groundbreaking research!

A Cure for Sophia and Friends

CHU Sainte-Justine

Université de Strasbourg
Excellence University

Everlum Bio

igbmc
institut de génétique et de biologie moléculaire et cellulaire

To our biggest Champions for a Cure,

CAPITAL GROUP™

THANK YOU!

rare village FOUNDATION

A Cure for Sophia and Friends would also like to thank Wittney Sadler, Roddra Johnson and Jerry Alamo for their assistance this year.

A Cure for Sophia and Friends Advisory Board: **Chelsey Oliver**, Secretary/ Associate Director, **Rischel Pike**, Treasurer/ Associate Director, **Reinhard Pell**, Advisory Board, **S Gary Sutherland**, Information Specialist/ Website Designer.