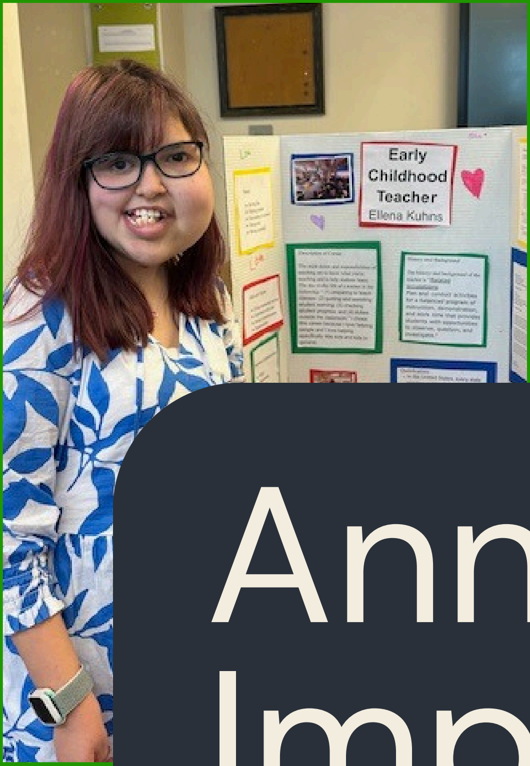

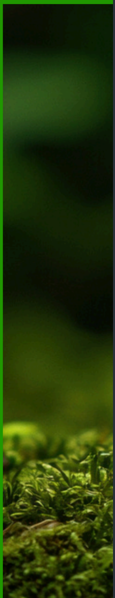

Annual Impact Report

CLOVES Syndrome Community

1-866-425-6837

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A year of Firsts

As I reflect on all this organization has accomplished in the past year, I am both humbled by this community's strength, and hopeful for our future.

The 2024-25 fiscal year was one of firsts for CSC. From our involvement with a new camp experience for families, to collaboration with Relay Therapeutics on their new clinical trial, there is so much to be grateful for and excited about.

Though the next years might bring unprecedneted challenges to our community, I remain confident in our ability to not only weather those challenges, but to rise above them together.

Lauren Beauregard, Executive Director

> “Finding the CLOVES Community changed my life completely. I grew up never seeing anyone like me, not even a bit. Now I feel so seen and represented by all the different people we see here on the community. All I have to say is thank you, with all my heart!”
>
> – Gabi, an adult with CLOVES from Brasil

40

Families directly served by CSC programs

~$20,000

Granted to individuals and families affected by CLOVES Syndrome

64K

Unique individuals reached through social media

Projects	Details	Outcome
Donation Platform Implementation & Migration	Migration to a new, more robust and modern donor platform to make donating easier, and more secure	• Saved $2400 annually • Successful 2-phase migration completed July 2025
Patient & Family Advisory Council Expansion	Expand the P&FAC with a focus on representing the lived experiences of our community	• Welcomed two new members to the council. • P&FAC now consists of 7 members; 3 adults with CLOVES and 4 primary caregivers
Strategic Communication Planning	Defining a sustainable communication plan for community and outreach messaging	• Social reach and engagement doubled compared to the previous year • Decreased administration time leaves more bandwidth for mission-driven programs

The year *in review*

CSC covered new ground this year while staying true to our mission.

New tools and initiatives in the 2024-25 fiscal year:

- New project management tool implementation (Monday.com)
- 30 Day Spark fundraising campaign
- Camp Korey Vascular Anomalies Family Camp
- New donor platform implementation (GiveButter)
- Board of Directors expansion (one new member)
- Patient & Family Advisory Council expansion (two new members)
- Young Adult Mentorship Program preparation
- Triage Health webinar partnership
- You Seem Curious cards introduced

Summer Highlight

2024 CLOVES Awareness Day brought with it new initiatives and resources for our community, while Back-to-School Bucks provided financial support to 20 families.

Autumn Highlight

Our 2024 Annual Appeal was our first campaign on our new donor platform, generating nearly $15K in donations. We also began collaboration with RelayTX on a hopeful new treatment, RLY2806 (ReInspire).

Winter Highlight

We had a blast with our Giving Tuesday Teams, and raised over $20,000 in support of CSC community programs. We were also awarded a $5,000 grant from Amgen in support of two key projects.

Spring Highlight

Spring brought our first ever 30 Day Spark campaign, and our first ever opportunity to speak at the International Drug Repurposing Conference, in Amsterdam. The ReInspire clinical trial opened, as well.

Finances

FY 24-25 FUNDS RAISED	$114,500
Donations	$101,000
Grants	$13,500
PROGRAM EXPENSES	$18,800
Family Assistance Program	$8,800
Back-To-School Bucks	$6,000
Other	$4,000
OPERATIONS EXPENSES	$90, 650
Fundraising Costs	$425
Travel + Training	$925
Office/Systems	$8,300
Payroll	$81,000
TOTAL SURPLUS	$5,050

Reserved for FY 25-26 Programs!

Funding summary

$101,000	$13,500
Donations	Grant funding

We'd like to thank all our donors for their *generous* *support*

Acknowledgements

We rely on an international army of volunteers, donors, experts, and supporters to help us fulfill our mission of improving the lives of those with CLOVES Syndrome and spreading awareness of this rare disease worldwide.

Your support makes all of this possible. Thank you.

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