CLOVES Syndrome Community

Impact Report

FY 2025-26

CLOVES SYNDROME COMMUNITY

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A Message from the Executive Director

There has never been a more hopeful time for the CLOVES Syndrome community.

New treatment options are on the horizon for our community. Researchers and scientists all over the world are studying the PIK3CA gene. It's easy to forget that many rare disease patient organizations like ours are still fighting for the attention we currently enjoy.

I am grateful for the groundwork CSC's founder, Kristen Davis, laid that made this all possible. And I'm so grateful for each person in the CLOVES community.

CSC's vision is "A world where people with CLOVES Syndrome live long, vibrant lives, with access to treatment options and excellent medical care."

We are closer to that vision than ever before, and getting closer every year. And that's definitely something to celebrate.

With hope and joy,

Lauren Beauregard
Executive Director, CSC

Impact Pillars

CLOVES Syndrome Community grounds its strategic and tactical planning in our core mission:

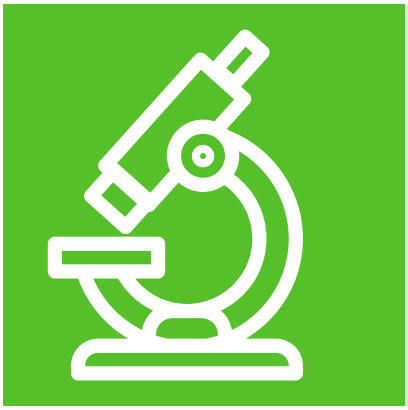
TO IMPROVE THE LIVES OF THOSE WITH CLOVES SYNDROME THROUGH SUPPORT, EDUCATION, AND RESEARCH

Support

CSC strives to connect members of the CLOVES community to one another online, and through in-person programs like Betsy's Camp & Retreat. The Family Assitance Program, and Back-to-School Bucks provide small scale financial support to help offset the cost of life with CLOVES.

Education

CSC strives to educate the CLOVES Community to allow them to advocate for themselves/their child through programs like CLOVES Syndrome Summit. We also educate the healthcare and scientific communities about life with CLOVES and our community's needs.



Research

CSC works with researchers, both academic and in the pharmaceutical industry, to ensure the CLOVES patient perspective is present in clinical trial and research protocol design. We also advocate for continued PIK3CA basic science research and support projects with seed funding when possible.

Measuring Impact

CSC saw growth across all key performance indicators this year, including welcoming 600 new members to the CLOVES Community across email and social media. We also welcomed 16 new participants to our patient registry, launched a new program for young adults with CLOVES Syndrome, and provided financial gifts to 58 families.

Financial Support

CSC provided 58 individual small-scale financial gifts to families during the 2025-26 fiscal year through our Family Assistance and Back-to-School Bucks programs. This is a 45% increase in families served over last year.

New Program

The Young Adult Mentorship Program was designed by members of the CLOVES community who saw a need to support people with CLOVES as they transition into adulthood. The program welcomed its first six mentees and three mentors this year.

Community Growth

We welcomed more than 180 new donors to the community, 125 of whom opted in to receive ongoing communication from CSC. Growing the community raises awareness of CLOVES Syndrome worldwide.

Social Reach

Social reach represents an opportunity to expand awareness of CLOVES. Instagram and Facebook followers increased by 340 collectively. LinkedIn followers increased by 19 (250 total). On YouTube, we gained 8 followers (75 total).

CLOVES Syndrome Registry

We welcomed 16 new members to the CLOVES Syndrome Registry this year, a 25% increase. Participants completed 57 surveys, contributing vital data for future research. We also approved the first request from researchers asking to access registry data to aid in academic research.

Finances

Sponsorships and grants from companies and foundations, along with an increase in individual donor giving have allowed CSC to increase investment in our mission-driven programs by 58%, while reducing our operation expenses by about $1000 year-over-year. (The figures below are rounded for simplicity of presentation and may not calculate exactly as shown.)

FY 25–26 FUNDS RAISED	$177,000
Donations	$111,000
Grants + Sponsorships	$61,130
Clinical Trial Consult	$1,400
Interest Earned	$3,460
PROGRAM EXPENSES	$50,560
Family Assistance Program	$17,870
Back-to-School Bucks	$5,260
Betsy's Camp & Retreat	$16,000
CLOVES Summit 2026	$2,400
CLOVES Patient Registry	$4,500
Bingo & Blossoms	$4,540
OPERATIONS EXPENSES	$95,250
Travel + Training	$7,200
Office, Insurance + Systems	$10,230
Payroll	$77,820
TOTAL SURPLUS	$29,000

Reserved for FY 26-27 Programs!

Looking Ahead

CSC's mission is to improve quality of life for people with CLOVES Syndrome through programs that support and educate our community, while building relationships with industry and academic researchers working toward a deeper understanding of CLOVES Syndrome and the development of new treatment options. During the 2026-27 fiscal year, our core projects will support this mission.

Website Refresh

A refreshed website experience will guide our most common types of users to the resources they need in a smooth, welcoming way. Newly diagnosed families and individuals will find clovessyndrome.org easily, and receive a warm welcome as they navigate the site.

Community Forum

The new home for the CLOVES Syndrome online community will be private, secure, and align with the community's priorities. Our community will be able to share and connect safely online, and CSC's communications will be less encumbered by social algorithms.

Patient Experience Survey

The PROS Treatment Landscape survey is designed to bridge the gap between clinical data and the lived experiences of the PROS community. By capturing patients' experiences, we can paint an accurate picture of PROS care and the need for continued research.

Expanded Volunteer Program

A formalized volunteer program will allow CSC to align with state work hour requirements for the facilitation of medicaid/medicare benefits for those elligible. Roles will be documented, while maintaining flexibility to embrace individuals' interests and skillsets.

Conclusion

We have accomplished so much in the last twelve months, and there is no doubt that we'll accomplish even more in the months to come.

Impact

We directly helped 58 CLOVES families, and grew the CLOVES Community by nearly 500.

Responsibility

We raised 28% more this year than the one before, while reducing operational expenses through streamlined processes and tools.

Movement

We will fulfil our mission in the coming year through four new projects designed to support our community and foster relationships with researchers.

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.

We would like to give a special thanks to

- The CSC Board of Directors
- The CSC Patient & Family Advisory Council
- The CSC Scientific & Medical Advisory Board
- The CLOVES Syndrome Registry Advisory Board

Your support makes this all possible.

Thank you!

Thank you, also, to our corporate and foundation partners this year:
Relay Therapeutics, Novartis, Hayes Family Foundation, and Althea's Footwear Solutions

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