



OVERVIEW

This strategic plan is the result of the two-day CLOVES Syndrome Community (CSC) strategic planning meeting held on November 1st and November 11th, 2020, and follow-up calls with Executive Director Kristen Davis and nonprofit consultant, Carrie Ostrea. CSC determined the critical issues to be addressed and discussed strategies to ensure a solid infrastructure, quality programming and services, and effective marketing and fundraising strategies. The goals, objectives, and strategies outlined in this 3-year plan are based on the issues and strategies discussed during the two-day strategic planning session with CSC leadership.

ABBREVIATIONS USED IN THIS DOCUMENT

CSC – CLOVES Syndrome Community

KOL – Key Opinion Leader

MSAB – Medical and Scientific Advisory Board

CZI – Chan Zuckerberg Initiative

RAO – Rare As One Project

P & P – Process and Procedure



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ORGANIZATION OVERVIEW

HISTORY OF ORGANIZATION

In 2009 the mother of a child with CLOVES Syndrome started a website and an organization, after she realized that no such resources existed for families and people with CLOVES.

One of the group's first major projects was in 2011 and was a convening at Boston Children's Hospital of six families with children with CLOVES Syndrome. It was at this meeting we were introduced to Dr. Matt Warman who took saliva samples from the attendees to try to determine the genetic mutation for CLOVES. It was this first meeting that led to the genetic mutation finding in 2012.

As more families joined CSC and physicians and researchers learned more about the syndrome and its complications, CSC increased its efforts to stimulate research on CLOVES Syndrome. Since 2016, CSC has dispersed \$108,000 in research funding to six institutions all around the world focused on CLOVES and PIK3CA Related Conditions.

We're part of the Chan Zuckerberg Initiative's Rare As One Network — a group of 30 patient-led organizations that are accelerating research and driving progress in the fight against rare diseases.

The Chan Zuckerberg Initiative's Rare As One Project aims to strengthen the efforts of patient-led groups. It will help communities of patients, researchers, and clinicians work together to advance progress against their diseases and scale these efforts. Working in partnership with the rare disease community, the Rare As One Project will create shared infrastructure to lower the barriers to patient-led research and enable patient communities to learn from one another. No one is more motivated than patients to drive progress against their disease. We're proud to be creating a patient-led research network to accelerate research and find treatment options for people with CLOVES and PIK3CA Related Conditions.

With its newly developed strategic plan, CSC can ensure that the mission, vision, and values of the organization are achieved.



ORGANIZATION OVERVIEW

PURPOSE

MISSION

CLOVES Syndrome Community supports, educates, empowers and improves the lives of those affected by CLOVES Syndrome.

Adopted: November 2021

VISION

An improved quality of life for people with CLOVES Syndrome.

Adopted: November 2021

STAKEHOLDERS

Our stakeholders are international and include: Individuals diagnosed with CLOVES Syndrome and their families, friends, and caregivers; physicians and medical and allied health professionals; researchers; therapists; teachers; biotech and pharmaceutical companies. CLOVES Syndrome-related foundations and nonprofit organizations; and individuals with PIK3CA Related Conditions and their associated patient advocacy organizations.



ORGANIZATION OVERVIEW

CSC TEAM

BOARD OF DIRECTORS

Lindsey Godar, Chair (MO)
Sara Robertson, Vice-Chair (TX)
Emily Burgess, Secretary (SC)
Ashley McNamara, Treasurer (OK)
Brenda Alexander (ME)
Joe Barclay (NY)
Kristen Davis (ME)
Alice Fuisz (DC)

STAFF

Kristen Davis (ME)
Shannon Burkoth (WI)
Ruth-Anne Pai (PA)

VOLUNTEER LEADERS

Lauren Beauregard (WA)
Robynn Kuhns (CO)
Jenny Padilla (NY)
Lindsay Passodelis (PA)
Kai Rehder (WA)



STRATEGIC GOALS AND PROJECTS SUMMARY

Goal #1: Organization Sustainability

Ensure that CSC is a financially secure, smoothly functioning, organization.

Goal #2: Promote education and awareness

Engage CLOVES Syndrome stakeholders, healthcare professionals, and the public through communication and education to foster awareness and improve quality of life.

Goal #3: Facilitate research

Engage CLOVES Syndrome and PIK3CA Related disorder researchers to seek opportunities and monitor ongoing research, recommendations, and clinical studies.

Goal #4: Support People with CLOVES and their families

Be responsive to the needs of the CLOVES community around the world with support and information, and community building opportunities.



STRATEGIC PROGRAM & GOALS

EVALUATION AND MANAGEMENT

Evaluation and management must go hand-in-hand with implementation of the CSC Strategic Plan.

Ongoing assessment is vital for several basic reasons: accountability, quality improvement, and predicting future needs and resources. Evaluation and management of the strategic plan will help to provide a clear understanding of the strengths and effectiveness of the organization's management and programmatic strategies and will help identify areas that need to be addressed and improved.

CSC will take the following steps to ensure implementation and evaluation of the CSC Strategic Plan:

- Request that each person(s) responsible for carrying out specific goals and objectives provide brief written reports monthly via email. Reports will be distributed in advance of board meetings to all board members.
- Assign a lead person (Program Director / Executive Director) to share a summary of written reports with the full board and use the strategic plan document as a guide for discussion and next steps.
- Modify the evaluation and management plan as needed.
- Thoroughly review, assess, and update the strategic plan annually, either in person or on zoom.



GOAL #1 SUSTAINABILITY

OBJECTIVE	NOTES
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GOAL #1: ORGANIZATION SUSTAINABILITY

Ensure that CSC is a financially secure, smoothly functioning organization.

Database Tech (CRM)	Complete
Staff Review and Needs Eval	Review Annually
Volunteer Management, Recruitment, P&P	Review Annually
Strategic Fundraising Plan	Develop Plan
Board of Directors Review and Needs Eval & P&P	Review Annually
Existing Strategic Plan Review	Review Annually
Restructure/Review CSC operational P&P	Review Annually
Additional Committee Needs Evaluation	Review Annually
Master CSC Calendar	Review Annually



GOAL #2

EDUCATION AND AWARENESS

OBJECTIVE	NOTES
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GOAL #2: PROMOTE EDUCATION AND AWARENESS

Engage CLOVES Syndrome stakeholders, healthcare professionals, and the public through communication and education to foster awareness and improve quality of life.

Community Building - Community calls	
One-Pagers / Collateral - CSC	
One-Pagers / Collateral - Registry	
One-Pagers / Collateral - Families	
Community Building - Video series for Scientific Meeting	
Community Building - CS Awareness Day	Aug 3 - Review Annually
Communication - Impact Report / Year in Review	Annually
Educational materials - Handbook	
Communication - Public Social Media (Review P&P)	Review Annually
Communication - Website	Review Annually
Community Building - Rare Disease Day	Feb 29 - Review Annually
Educational materials - Webinar series	
HCP Outreach - Exhibiting at conferences review	ISSVA/Oncology
HCP Outreach - Grand rounds / medical schools	



GOAL #3 RESEARCH

OBJECTIVE	NOTES
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GOAL #3: FACILITATE RESEARCH

Engage CLOVES Syndrome and PIK3CA Related Disorder researchers to seek opportunities and monitor ongoing research, recommendations, and clinical studies.

Scientific Conference Hosting	October 2021
Monitor and track ongoing research	Ongoing
Creation of a PIK3CA related conditions research network	Ongoing
Identifying medical/research needs of people with CLOVES	Ongoing
Identify knowledge gaps	Ongoing
Patient Registry	Ongoing
Educate families about participating in clinical studies	Ongoing
Expand Medical and Scientific Advisory Board	TBD
Develop relationships with pharmaceutical companies	Ongoing



GOAL #4 SUPPORT

OBJECTIVE	NOTES
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GOAL #4: SUPPORT PEOPLE WITH CLOVES AND THEIR FAMILIES

Be responsive to the needs of the CLOVES community around the world with support and information, and community building opportunities.

Annual Conference	Every odd year
Facebook Moderation	
Needs Assessment for Support Initiatives	
Translating information into multiple languages	
Camp	Annual
Adult patient outreach Plan	Review Annually
New Family Welcome Process Evaluation	Review Annually
Regional meetings Plan	Review Annually
Family Assist /Back to school Bucks Evaluation	Review Annually

BASIC SCIENCE

PROJECT DESCRIPTION	PROJECT PARTNER	BEGINNING DATE	ANTICIPATED COMPLETION	CSC ROLE	CSC SUPPORT
The systems biology of activating PIK3CA mutations in mosaic endothelial cell models	Ralitsa Madsen	March 2020	Sept 2021	Funding	\$20,000
CLOVES/PROS Literature Review	RAO Science Advisor	June 2020	Ongoing	Direct work with Science Advisor	\$5,000
Identifying the molecular impact of PIK3CA variants in PROS towards stratification of patients and personalized medicine	Ana Angulo-Urarte	June 2021	September 2022	Funding	\$25,000

TRANSLATIONAL RESEARCH (DRUG SCREENING / PRE-CLINICAL)

PROJECT DESCRIPTION	PROJECT PARTNER	BEGINNING DATE	ANTICIPATED COMPLETION	CSC ROLE	CSC SUPPORT
Generation of PIK3CA mouse models	Boston Children's Hospital/Matt Warman	2016	2019	Funding	\$6,000
Generation of PIK3CA zebrafish models	Boston Children's Hospital/Matt Harris	2018	2019	Funding	\$4,000
Investigation of PIK3CA mouse models + drug screening	Canaud Lab	2018	2021	Funding	\$30,000
Efforts to provide drug repurposing for CLOVES	RAO Science Advisor	2020	Ongoing	Funding	\$2,000

CLINICAL RESEARCH (NATURAL HISTORY / RISK FACTORS / IMAGING)

PROJECT DESCRIPTION	PROJECT PARTNER	BEGINNING DATE	ANTICIPATED COMPLETION	CSC ROLE	CSC SUPPORT
Neurological Complications of CLOVES	Boston Children's Hospital Vascular Anomalies Center	2017	2021	Funding; Support of the Lymphatic Anomalies Registry	\$14,000
Advocacy for non-surgical treatment	PROS Organizations	2015	Ongoing	Shape research and clinical practice	Collaboration and networking
Clinical trial support and recruitment	PROS organizations and pharmaceutical companies	2019	Ongoing	Inform proper endpoints, educate and support CLOVES community	Collaboration and networking
CLOVES Contact Registry	N/A	2014	Ongoing	Connect, educate, and support CLOVES community; identify demographics	\$15,000
Stakeholder interviews to capture patient voice and expert opinion	RAO Science Advisor	2020	Ongoing	Direct work with Science Advisor	\$2,000
Kahle Lab AVM Research	Kristopher Kahle, Yale	2020	Ongoing	Educate and support CLOVES community; connect to clinical research	Posted on CSC website
First in Human Trial of Topical VT30 in Pts With Venous/Lymphatic Malformations Assoc With PIK3CA or TEK Gene Mutations	Venthera	2020	Ongoing	Educate and support CLOVES community; connect to clinical research	Collaboration and posted on CSC website

RESEARCH INFRASTRUCTURE

(CSC has consulted, supported, or completed projects to support outside partners or drive other research projects forward)

PROJECT DESCRIPTION	PROJECT PARTNER	BEGINNING DATE	ANTICIPATED COMPLETION	CSC ROLE	CSC SUPPORT
PIK3CA Related Conditions International Patient Registry	TBD	2021	Ongoing	Funding for infrastructure support and data analysis	TBD approx. \$30,000
Vascular Anomalies Communication (VACOM) Study	Dr. Bryan Sisk and Dr. Anna Kerr	2021	2023	Collaboration for recruitment, information sessions and webinars	\$10,000