DOWN SYNDROME ASSOCIATION of CONNECTICUT













Our Vision

A world where people with Down syndrome are supported and empowered.

Our Mission

To encourage intentionally inclusive communities while providing resources and support to individuals who live with Down syndrome and their advocates.

Overview

DS ACT was started in 1986 as the Connecticut Down Syndrome Congress (CDSC) by parents wishing to improve the opportunities available to their children with Down syndrome. In 2016, our name was changed to better reflect growth in programming and advocacy. We now serve nearly 500 member families and collaborate with a variety of other non-profit organizations. Our statement of principles is available at www.mydsact.org/about-us.

Programs

First Call New Parents and Siblings and Medical Outreach We train volunteers to support new and expectant parents and siblings of children with Down syndrome, and we share information with the medical community.

DS ACT Literacy and Education Center An initiative to support individuals with a Down syndrome learning profile through one-to-one and small group tutoring. The Center can also provide professional development and support to Connecticut school districts, and training and research opportunities.

IEP Mentoring We provide one-to-one Individual Education Plan (IEP) mentoring to DS ACT members and wok closely with the Connecticut Parent Advocacy Center.

DS ACT Advocacy Avengers We facilitate a group for teens and adults who live with Down syndrome where they can practice social, advocacy and independent living skills in a fun, affirming and thought-provoking environment

DS ACT Mini Grants We financially support opportunities for community integration and inclusion of individuals who live with Down syndrome.

DS ACT Camp Grants DS ACT families are granted up to $500 to defray the cost of summer camp for their loved one with Down syndrome. This provides an opportunity for independence for the individual and a form of respite for caregivers.

Family Support Groups We hold social events for our members and sponsor a network of regionally-based family support groups.

Sunshine Committee Utilizing personal donations, personal connections and some DS ACT resources, the committee provides highly individualized "under the radar" support to families in need, ranging from those encountering financial hardship to those with a loved one in the hospital who need a small pick-me-up.



DS ACT Awareness Committee In October and on World Down Syndrome Day in March, we host public events celebrating the potential and accomplishments of individuals with Down syndrome; we facilitate donations of books about Down syndrome to schools and libraries; and we use social media campaigns to raise awareness.

DS ACT Step Up for Down Syndrome Walk Committee The Step Up Walk is our primary fundraiser and our largest public event. It celebrates the potential of people who live with Down syndrome and raises awareness.



DS ACT Fundraising Committee Among the committee's goals is to position DS ACT for growth and sustainability through expansion and diversification of fundraising streams.

Educational Events We educate and advocate for best practices in medical, educational, and therapeutic interventions through workshops, public presentations, legislative testimony and outreach efforts.



DS ACT Media Team We foster communication and share information using our website, social media, and e-newsletter.

DS ACT 800 Line We provide phone support to anyone in Connecticut with a concern related to Down syndrome.

Size and Scope of Organization

Our annual budget $215,000+ budget is derived from the Step Up Walk, membership dues, general donations, and grants.

Presently, we employ a full-time executive director, a quarter-time operations coordinator, three quarter-time support group facilitators, a quarter-time literacy program research coordinator, two quarter-time literacy associates, and a quarter-time literacy teaching assistant. The teaching assistant position is held by an individual who has Down syndrome.

We also employ a quarter-time First Call coordinator. Contract workers are paid for administrative support and tutoring in our Literacy Center. We contract with a bookkeeping service and a CPA for bookkeeping, tax preparation, and financial review.

The Present Board

The board of directors meets from 6 pm to 9 pm on the third Wednesday of every month from January through June and in October, November, and December. Additional meetings may be scheduled in July, August, and September as business demands. The board may occasionally hold a meeting in person. This scheduling may change in response to strategic planning goals.

The board is a working board comprised of up to twelve directors who serve a maximum of three two-year terms. The DS ACT executive director serves on the board in an ex officio capacity with no voting rights. Committees are determined by strategic and support needs may convene between meetings.

New Directors Being Sought

Of particular interest are individuals with fundraising, marketing/media, and human resources connections and expertise.

Responsibilities

Regular attendance at meetings; service on a committee as needed; attendance and participation in our Step Up Walk, and social and outreach events, contribution to our fundraising effort by holding a fundraiser, leading a Step Up Walk team, sponsoring a table at our gala, or through meaningful personal contribution.

Insurance Coverage and Legal Obligations

DS ACT carries General Liability and Special Events insurance coverage, as well as a Directors and Officers Liability policy. We are a federally recognized 501(c)3 organization, incorporated in the State of Connecticut. We comply with all federal, state and local laws.

For Further Information or to Apply for a Position Contact

Shanon McCormick, executive director
smccormick@mydsact.org
888-486-8537
66 S. Broad St., Unit 1082, Pawcatuck, CT 06379
www.mydsact.org
EIN: 06-1176478