



2018 has been a watershed year for the Down Syndrome Association of Connecticut (DS ACT). In 2012, DS ACT, then known as the Connecticut Down Syndrome Congress, was in a state of organizational crisis. Several board members had resigned, programs were faltering and members were drifting away, at best disillusioned, at worst, angry.

Directors remaining on the board set about revising the by-laws, shoring up our internal structure and processes and, with the help of DSAIA, Connecticut ProBono Partnership and a few local non-profits, turned the organization around. Throughout this time, we have looked to DSAIA for training, connections, resources, webinars and moral support. It is impossible to understate the role DSAIA has played in saving this organization.

Working from a strategic plan initiated in 2015, we have introduced or completed a number of projects this year:

#### Rebranding

We completed rebranding that included a name change, revised collateral materials and a new website.

#### Increased Membership

At 499 members as of January 23rd, we are only one new member shy of meeting our goal of growing from less than 400 to 500 members.

#### New Programming

- We launched and continue to build the *Advocacy Avengers*, 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.
- We launched the first *Siblings First Call* program in the country. Siblings First Call matches brothers and sisters who are expecting a new sibling with Down syndrome with similarly aged peers for emotional support and friendship. Run by teens with oversight from our First Call coordinator, the program has assisted DS groups in other parts of the country in setting up Siblings First Call programs in their area, as well.

### New Services

With research finding garnered from a pilot study funded by the Global Down Syndrome Foundation in 2017, we launched the DS ACT Literacy and Education Center, an initiative to support individuals with a Down syndrome learning profile from age five through adulthood with one-to-one and small group tutoring. The Center is also beginning to provide independent academic evaluations, professional development and support to Connecticut school districts, and training and research opportunities. We believe the Center is the only one of its kind in Connecticut in that our intent is to not only support students with Down syndrome, but also to improve schools overall by supporting best practices in education through research and training.

### Expanded Current Services

- We expanded a collaborative venture with the Connecticut Parent Advocacy Center (CPAC) to staff an *IEP Mentoring* program for our membership.

A parent coach trained in advocacy by CPAC receives additional training in the Down syndrome learning profile. With DS ACT funding, the coach is then available to our members to provide one-to-one support and coaching up to and including attendance at IEP team meetings. This mission-driven program works to empower parents as members of the IEP team. The parent coach also collaborates with the Literacy Center to address student needs in the tutoring program and to help parents resolve points of friction with schools before they rise to the level of disputes.

- We continued to expand our *First Call New Parent* support program and began laying the groundwork for a medical outreach program that extends beyond delivery of a diagnosis throughout the lifespan.

The idea to connect with the medical community on issues beyond those that are encountered pre- and post-natally arose from (1) the increased number of calls about adult medical needs to our 800 line, (2) the work we have been doing with a consortium of disability organizations to improve access to healthcare for individuals with intellectual and developmental disabilities in Connecticut, and (3) our financial support of the Global Down Syndrome Foundation's Medical Guidelines for Adults with Down Syndrome.

- Utilizing personal donations, personal connections and some DS ACT resources, our extended family support committee provided highly individualized "under the radar" support to families in need, ranging from helping those facing financial or other personal hardship to cheering up those with a loved one in the hospital who needed "a little sunshine" in the form of a visit from a volunteer bearing gift cards (and dressed in costume when appropriate).

### More Public and Members' Only Events Than Ever Before

- We educated and advocated for best practices in medical, educational and therapeutic interventions through workshops at our annual statewide convention, featuring Dr. David Stein as our keynote speaker.
- For World Down Syndrome Day we hosted public events at two locations (up from one in previous years) celebrating the potential and accomplishments of individuals with Down syndrome; we facilitated donations of books about Down syndrome to schools and libraries; and we used social media campaigns to raise awareness.
- Our family support groups hosted get-togethers, Moms' Nights Out and special events. In total, we raised awareness, challenged stereotypes and strengthened our social connections with more than 30 events through the course of the year.

### Improved Visibility and Communication with the Public

- We initiated the *Many Hands Awards*, annual recognition of those inside and outside the Down syndrome community in Connecticut whose actions support and empower us.
- Drawing largely from webinars and resource materials in the DSAIA library, we enhanced our social media presence, more than doubling our "likes" on Facebook, and we initiated use of an editorial calendar and a more organized and streamlined process for sharing information.
- We parlayed media connections made during the Buddy Walk into additional exposure later in the year.

### Increased Fundraising

We raised \$134,000 at our Buddy Walk, an all-time high. We welcomed recognized more sponsors than ever before. We are planning an inaugural 10k/5k in 2019, drawing from information presented at a DSAIA workshop.

### Consistency in Program and Service Delivery by Shifting from Volunteer to Hired Staff

We now have a full-time executive director and a full-time literacy program coordinator on staff. We employ a part-time First Call coordinator, a part time literacy training and research coordinator and contract staff to facilitate the self-advocates' group.

In 2019 we will be reaffirming our commitment to our mission by drafting a new strategic plan and by putting a development plan in place. Grateful for the significant and ongoing support we receive from DSAIA, we will also be rolling up our sleeves to begin transitioning from a working board to a governing board of directors.