

cdsc
CONNECTICUT
down syndrome
CONGRESS



2016 Annual Report

November 5, 2016

Letter from Our Board of Directors

Dear Connecticut Down Syndrome Congress Members and Friends,

As president of the Connecticut Down Syndrome Congress and on behalf of your Board of Directors, I wish to welcome you to the 31st Annual Connecticut Down Syndrome Convention, as we begin our fourth decade of convention-ing here at the grand Water's Edge facility in the scenic waterfront town of Westbrook, CT.

As this year's Down syndrome awareness, advocacy and events come to a close, I see an exciting future before us. In the next year the "look" of our organization will change as we sharpen our efforts to fulfill our mission. I would really like to give more details but the others will not let me – wait until the business meeting they say.

Your continued support of and participation in the events that make up "Down syndrome season" remain high. With the growth of our the First Call Program, expansion of the county support groups, and improved outreach & communication things will get even better as we move forward. I expect 2017 will bring with it completion of the goals the board set for itself in its strategic planning process two years ago.

Whether you are a first-timer or whether this is a return visit to our convention, it will be a wonderful way for you to power up and gain knowledge and insight into the Down syndrome community. For you returning folks who have done this before – and for some of you, it could be many, many times before – I encourage you to continue expanding your horizons so you can meet that next transition head-on. Were you empowered by last year's convention? Did something you helped with get profiled in this year's annual report? Were you recognized for your involvement with an event or program? As an organization, we are at our best when our members are active and visible.

The timing of this year's convention brings with it increased opportunity to energize for activism, since it falls just before Election Day. Say what you want about the Presidential situation but state and local elections are extremely important – please vote!

Enjoy your day here in Westbrook making connections at the convention and keep this message close to your heart for the rest of the year: **power up, charge up and never give up!**

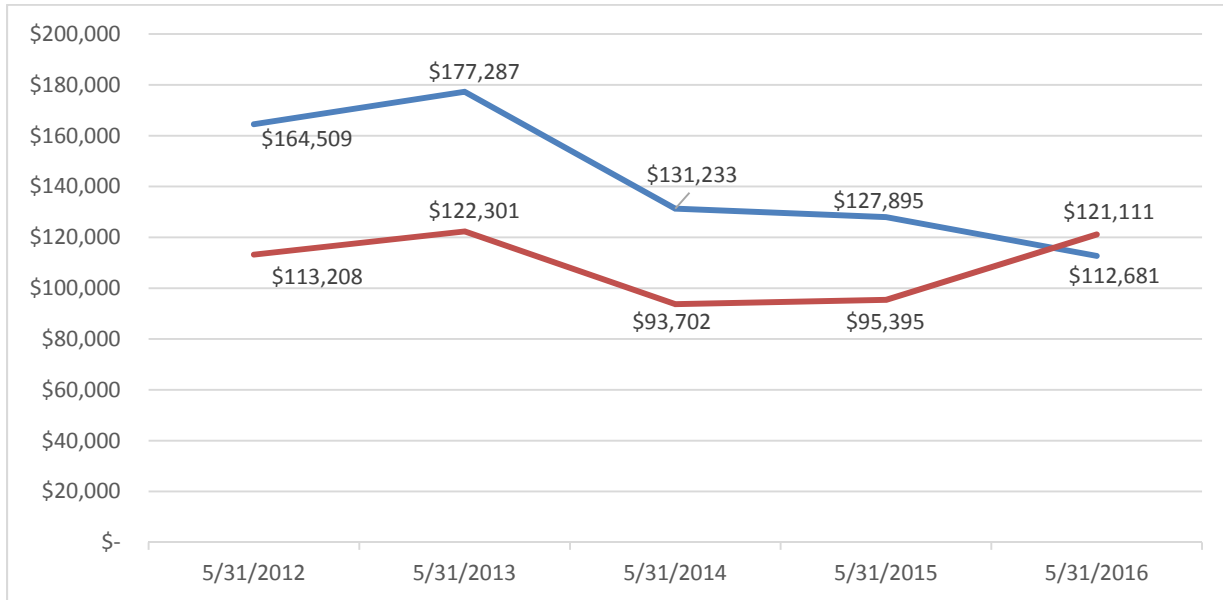
Sincerely,

Alan D. Llewelyn

Alan D. Llewelyn
President – Board of Directors
Connecticut Down Syndrome Congress

2016 Highlights – Organization Statistics

Revenues and Expenses by year: Changes in revenue are generally in line with our turnout at the Buddy Walk and expenses generally coincide with revenues. In 2016, expenses exceeded revenues for the first time in a number of years due to additional spending on the 2015 convention and additional 2016 seminars and workshops.



Other relevant statistics: It has been a busy year for the CDSC, some statistics to share are as follows:

Increased Assistance:

- 314 Email Requests for Assistance or Information
- 78 Calls to our Toll-free Number for Assistance or Information
- 60 Inquiries to First Call for New Family Information and Support

Grants and Aid:

- Mini Grant — Books on Down Syndrome to Manchester Public Schools
- 15 Camp Grants
- 1 financial and 1 in-kind sponsorship — Arc of CT and CT Cross Disability Lifespan Alliance

Events

- Educational Workshops: IEPs, Behavior, Nutrition
- World Down Syndrome Day Celebration
- 3 Major Regional Social Events — Spring Fling, Summer Picnic and Boo Bash Halloween Party
- Music Therapy Classes
- Dance and Movement Classes
- Annual Buddy Walk
- Annual Convention

2016 Highlights – Collaboration

Collaboration is central to the CDSC's success. Working closely with other organizations helps us expand program offerings and reduce overhead.

Our most significant collaborative relationships in the past year have involved the Connecticut Parent Advocacy Center (CPAC) and the Arc of Connecticut. CPAC is a full partner in providing IEP mentoring to our members through our First Steps program, and we maintain an active dialogue regarding ways the two organizations can support one another administratively and financially. The Arc of Connecticut serves as the CDSC's eyes and ears in Hartford, and continues to be a strong voice for the needs of our adult members who live with Down syndrome and their families. We are especially grateful to have the Arc's Families for Families leading the way in legislative initiatives.

More recently, the CDSC reached beyond the disability community in its collaboration efforts, participating for the first time in an amazing event – a Hackathon – created by Random Hacks of Kindness, Jr.

Random Hacks of Kindness, Jr. is an educational organization in Connecticut that empowers students to use technology to meet the challenges facing local non profits. At its one-day "Hackathons," fourth through eighth grade students are paired with computer science mentors and nonprofit representatives to develop prototype smartphone apps.

In celebration of Down Syndrome Awareness Month in October, Board president Alan Llewelyn gave a presentation at the Hackthon about the CDSC and then the students went to work, creating a prototype app just for us.

Participating in the Hackathon gave us a chance to dream big about how technology can be harnessed to enhance communication, learning, and employment for people with Down syndrome, as well as how we might support them in learning technical skills themselves. More immediately, the collaboration allowed us to raise awareness about Down syndrome among students and interact informally with other organizations in attendance. We look forward to strengthening our connection to Random Hacks of Kindness, Jr and continuing to build partnerships with other organizations.





2016 Highlights — 13th Annual Buddy Walk



Congratulations to our 2016 top teams:

1. Winner: Grace's Gang/ Team Lombardo \$10,785



2. Runner Up: Team Pro \$8,700



3. 3rd Place; Yasmanian Devils \$5,111 <no picture ☹>





Thank You to our 2016 Buddy Walk Sponsors



Financial Audit

We have successfully completed our 4th Annual financial statement audit. We are happy to announce that we are expecting to receive an unqualified (clean) opinion as of and for the year ended May 31, 2016.

A special thanks to Darin Offerdahl and his team at Michaud, Accavallo, Woodbridge & Cusano, LLC!

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2016 Highlights – Coming Soon

New Name and Logo Coming

In accordance with the goals laid out in our strategic plan and after a year of internal study and consultation with a branding expert, the CDSC board of directors is excited to begin implementing a rebranding effort. In the coming year, our new name and logo will be unveiled and our website will be redesigned and refreshed. The new name and logo will focus on exactly what type of organization we are and will emphasize what is important to us. We feel this new name and look will provide those outside our organization with transparency and will heighten awareness of our mission.

Important Educational Collaboration

The CDSC has continued its collaboration in 2016 with the Connecticut Parent Advocacy Center (CPAC) on the First Steps IEP Mentoring Program. With CDSC financial support, a CPAC staff member received additional training in the Down syndrome learning profile and is now providing one-to-one support to our families as they develop IEPs. While the pilot program focused on Hartford County, we have now expanded the program statewide. CPAC and the CDSC continue to monitor the program's success and fine tune it to meet our members' needs.

Camp Grants

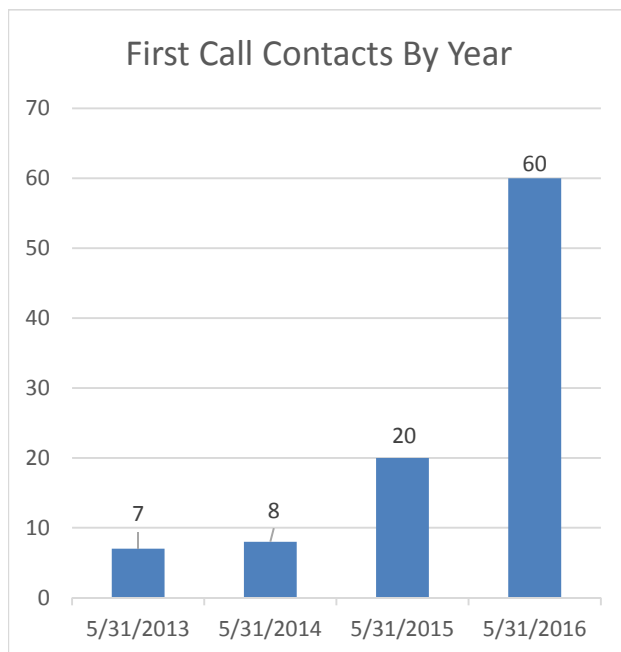
Three years and going strong. Our 2016 camp grants distribution was our highest year yet and we are hoping to keep it rolling. We awarded 16 grants ranging from \$250 to \$500. The larger grants were for overnight camps while the smaller ones tended to be for day camp experiences.

We will be distributing annual grants of up to \$500 to help pay for camp for individuals with Down Syndrome. Applications are accepted on a rolling basis beginning March 1st. An application consists of the following: Your name, address, phone number, email contact, your child's name, age and the name of the camp the child will be attending. A short statement of why you need the award should be included. Email your application to campgrants@ctdownsyndrome.org.

2016: First Call Program



This has been a very successful year for our First Call Program. We receive calls from Birth to Three agencies, social workers and expectant parents/ new parents.



One of the main drivers has been the increase in Spanish speaking volunteers. With the help of these volunteers, new Spanish speaking families are given materials in Spanish and have a Spanish speaking family as a contact for support. Another big driver has been the support of hospitals sharing our materials, most notable were Stamford Hospital and Yale Hospital. In other First Call news, we have an active private First Call Families FB group. Parents welcome each other and share advice and ask questions to one another. Organized playgroup get together are in the works for our new families.

Our Board of Directors

President - Alan Llewelyn allewelyn@ctdownsyndrome.org

Vice President - Shanon McCormick smccormick@ctdownsyndrome.org

Secretary - Emily Kalenauskas ekalenauskas@ctdownsyndrome.org

Treasurer - Ted Lucas tlucas@ctdownsyndrome.org

First Call Coordinator – Patty Alessandro firstcall@ctdownsyndrome.org

Immediate Past-President Brian K. Morley bmorley@ctdownsyndrome.org

At large Directors - Joseph Dennin jdennin@ctdownsyndrome.org

Brooke Daly bdaly@ctdownsyndrome.org

*We are currently taking applications for new directors. We strongly encourage those individuals interested to contact one of our board members.



A big thank you to our convention committee members: Karen Konatich-Sawyer, committee chair, Patty Alessandro, Emily Kalenauskas, Alan Llewelyn, Shanon McCormick and Marcia Munson. And many thanks to our friends at the Water's Edge Resort.



Special thanks to our convention partner, Power Station Events, for their audiovisual support this year.

