

cdsc

CONNECTICUT
down syndrome
CONGRESS



2014 Annual Report

November 8, 2014

Letter from Our Board of Directors

Dear CDSC Friends and Family Members,

2014 has been another incredible year of growth for the Connecticut Down Syndrome Congress.

As you will see in this report, we have continued to strengthen our internal structure and controls to assure the stability of the CDSC and to improve our ability to meet members' needs. With the help of a near-record 1400 participants at our annual Buddy Walk this year, we again raised thousands of dollars for advocacy, education and member support. As a result, the number of paid memberships in the CDSC is the highest it has ever been and outreach efforts to new parents through our First Call program are flourishing.

2015 promises great things. The CDSC is collaborating on a new advocacy education project with the Connecticut Parent Advocacy Center (CPAC) in efforts to benefit not only our members, but also others families in the state who share the experience of navigating life with disability. We, of course, continue collaborations with national advocacy organizations like the National Down Syndrome Congress, the National Down Syndrome Society, and the Down Syndrome Affiliates in Action. The Board of Directors also intends to focus on strategic planning for the coming years, so that we might make the most of our recent hard work.



As many of you now know, I will be stepping down as board president at the end of this year, in order to take a job in another state. Stepping down at this time is bittersweet, since I had hoped to continue on the board as we develop plans for the future. I will have the pleasure of serving in a limited capacity as immediate past president for the next year or two, so I hope to remain a part of the exciting developments in the CDSC's history, if only at a distance.

I am confident that my successor will capably guide the CDSC toward fulfillment of its mission in coming years. Thank you for allowing me to serve our community – it has been an honor.

Sincerely,

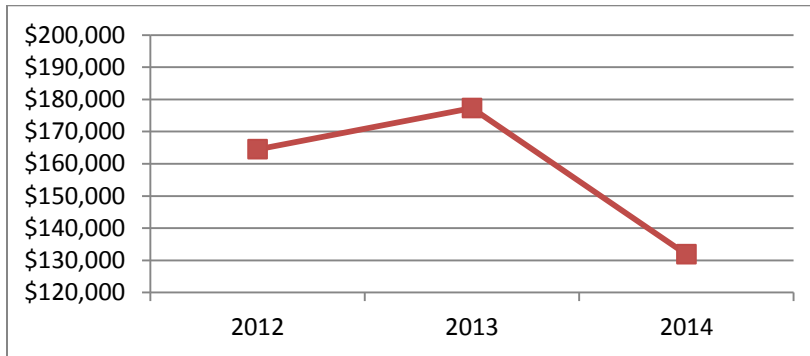
A handwritten signature in black ink that reads 'Brian K. Morley'. The signature is written in a cursive, flowing style.

Brian K. Morley, President

2014 Highlights – Organization Statistics

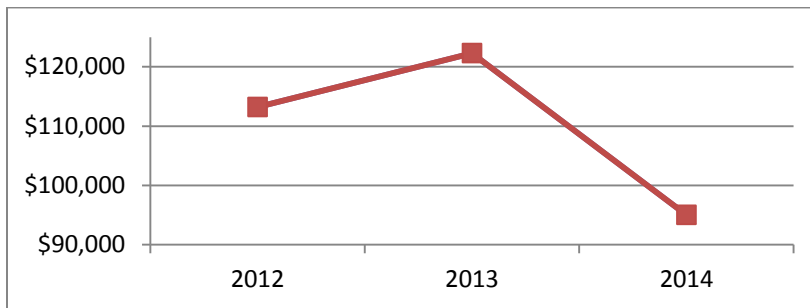
Below are some organizational and financial results our Organization has achieved within recent years. These statistics have been compiled using our audited financial statements.

Revenues by year:



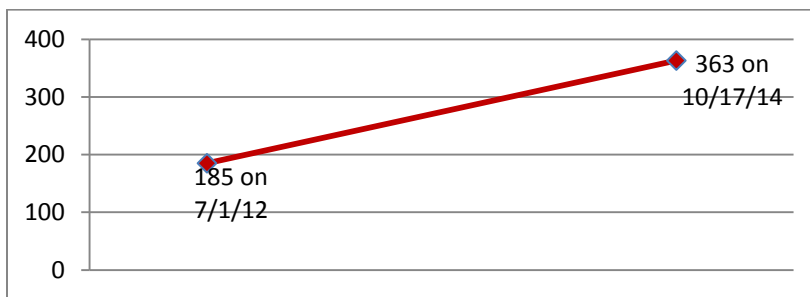
Changes in revenue are generally in line with our turn out at the Buddy walk. The high point in 2013 was due to a one-time large donation earmarked for our First Call Program.

Expenditures by year:



Expenditures were at their highest when the Organization donated \$66,000 to CCMC in 2013, and have generally coincided with revenues.

Membership by year:



Membership continues to grow. From 2012 to 2014, membership has increased by 178 members or 96%.

2014 Highlights – Advocacy: Families for Families and First Steps

The CDSC continues to work closely with the Families for Families group at the Arc of Connecticut to improve the delivery of services from the Connecticut Department of Developmental Services. A CDSC representative attends leadership meetings as well as monthly meetings with the Commissioner of the DDS, Terrance Macy.

Families for Families initially worked with Representatives Beth Bye and John Case to establish the I/DD Caucus so state legislators can be informed about issues important to people with intellectual and developmental disabilities. During the last session, Families for Families successfully lobbied to allocate 4 million dollars for moving people currently on the waiting list for housing into arrangements tailored to their needs and preferences, rather than awaiting emergency placements when their last caregiver dies.

In October, the CDSC board announced that it had signed an agreement with the Connecticut Parent Advocacy Center (CPAC) to develop a new IEP training and mentoring program called First Steps. The first phase, a pilot study to be conducted in Hartford County through June 2015, will provide training and services to CDSC members, while further defining how the First Steps program will be delivered. A CPAC staff member with additional training in the needs of children with Down syndrome will work one-on-one with CDSC member families to evaluate their child's current IEP and then train and model appropriate advocacy techniques.



In later phases, the program is expected to expand throughout the state. The first collaborative effort of its kind between CPAC and an organization like the CDSC, it is hoped that it will support CDSC families with direct services, support the disability rights community by identifying strong candidates for further advocacy training and, finally, that it will serve as a model of collaboration and service delivery for other organizations.

2014 Highlights – First Call Program

This past June, The CDSC First Call Program celebrated its second year as a functional support group for new and expectant parents. Patty Alessandro, a longtime CDSC member and the parent of a son who has Down syndrome, is the First Call New Parent Coordinator. Under her direction and with the support of the CDSC board of directors, First Call continues to grow.

New and expectant parents can reach First Call through the CDSC toll-free number or by email. Patty typically receives four, but up to seven contacts a month through these channels. She also receives referrals from other parent organizations, hospitals, OB physicians and Birth-to Three agencies.

Patty makes contact with new and expectant parents in less than 24 hours. The proportion of calls from parents very early in their pregnancy – as early as 12 to 14 weeks -- grew dramatically this year, due to the availability of the Materna21 blood test. Patty listens, and then provides referrals and mails out appropriate materials, based on their conversation. Supported by a generous grant from the WIN-WIN foundation, we are able to keep a stock of publications, including, Parents' Guide to Down Syndrome, and Faces of Hope and Gifts, so that they can be sent out immediately.

After that first conversation, Patty identifies one of more than 20 volunteer families throughout the state to follow-up with the new parents to talk, ease fears and answer their "what if" questions. Many volunteers were once First Call Families themselves.

First Call also supports families who are non-English speakers. We have four Spanish-speaking volunteers who make the initial contact with Spanish-speaking families and then Patty follows up with the materials they need. Patty has also successfully tracked down materials in Arabic and Mandarin Chinese.

Finally, Patty has set up a First Call Families private page on Facebook. It is a great way to send articles of support, celebrate births and birthdays, and for new and expectant parents to ask questions of one another.

Every phone call this year from a scared, unsure parent ended with a birth of a beautiful new baby in our community. There are still many families to reach, but Patty and her volunteers have done an amazing job of letting newly diagnosed parents know not only that they are not alone, but also that the support available within our community is endless. There is no better joy than seeing families come together at the picnic, Buddy Walk and family birthday parties. Where once they were strangers, they now share a bond they never expected or thought possible.



"He's here! He's amazing and my heart melted the second I saw him. He is perfectly imperfect. I now know what you have been saying all this time. I love him so much my heart could burst...Thank you for being a great friend and mother who helped me through such a hard time in my life."

-- A First Call New Parent

2014 Highlights – 11th Annual BUDDY WALK

Congratulations to our 2014 Buddy Walk top teams:

1. Team PRO Captain: Mike O'Rourke



2. Skye's Team Captain: Margarito Rodriguez



3. Team Lombardo - Grace's Gang Captain: Guisela Lombardo



Thank You to Our 2014 Buddy Walk Sponsors



2014 Highlights – Scholarship and Mini Grants

Congratulations to our 2014 Scholarship winner

Each year the CDSC awards a scholarship to a deserving student pursuing a master's degree in special education who intends to work with students who have Down syndrome after graduation.

This year \$1,000 was awarded to Katherine Rupp, a student in the special education master's program at Fairfield University. Ms. Rupp works as an elementary school paraprofessional while pursuing her graduate studies.

Two Mini Grants Awarded

Mini grants are grants of up to \$500 awarded to organizations to assist them in their efforts to increase awareness of the potential of people who live with Down syndrome and/or support inclusion and participation in school, the workplace or the community. This year, two grants were awarded. The first was to t. Mark's Toddler Playgroup in Mystic, CT. The Toddler Playgroup is a highly regarded fully inclusive preschool setting for children ages two to three years. The grant supported the purchase of wall mats to improve safety in the gym. The second grant was to New England Business Associates (NEBA), an adult employment services non-profit, for purchase of an iPad to support a young man with Down syndrome in his development of work and independent living skills.

2014 Highlights – Hartford County Dance and Movement

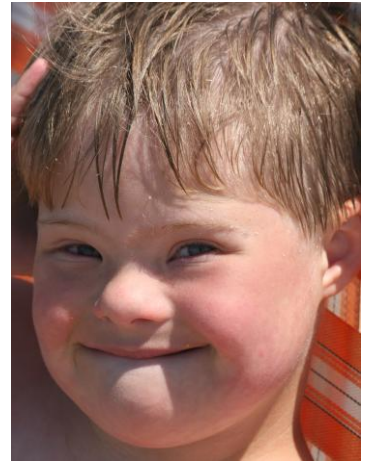
Kayla Rodriguez teaches the Creative Movement Workshop at the Dance 10 Studio in Wethersfield in cooperation with the CDSC. In a short time, Kayla has become a true friend to the Down syndrome community. A recent graduate of Roger Williams University, she works with preschool children who have special needs in Wethersfield during the week, but one Sunday a month, she shares her skill and love of dance with the CDSC as a volunteer.

Kayla contacted the CDSC with the idea of starting the workshop in 2013, about a year after graduating, cum laude with a B.A. in Dance Performance and Psychology. While she says she has always been interested in working with people with special needs, her interest was really piqued while completing an internship at Life Incorporated Rhode Island, an organization that provides support and residential services to people with intellectual disabilities. Her work there involved holding biweekly dance classes for adults with developmental disabilities.

The Creative Movement Workshop meets monthly. Creative movement uses dance/movement to explore feelings, thoughts, ideas, and concepts. It is an essential part of development in children and an excellent way for them to explore and learn about their bodies, space, time, and about the world. Exploration of movement helps children grow emotionally, socially, physically, cognitively and musically.

Kayla started the Workshop with one "all ages" class, but this spring added a class for the older kids (8 to 14) as well. Because of Kayla's longstanding relationship with the owner of the Dance 10 Studio in Wethersfield, studio costs are reduced for CDSC member families.

Karen Konatich-Sawyer, a Hartford County Family Support Coordinator, and mom to Regan, one of the workshop participants, said, "Kayla is truly amazing. She loves our kiddos and puts her whole heart into creating a program that they will enjoy. Kayla is a wonderful friend to the Down syndrome community we are so lucky she found us!"



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2014 Highlights - Raising Awareness and Driving Change

Educating our membership, the public and our legislators about the needs and potential of people who live with Down syndrome is at the heart of the CDSC's mission. Here are some examples of our efforts this year – both on our own and in cooperation with other organizations.

- First Call Coordinator Patty Alessandro and Board Secretary Shanon McCormick appeared on Channel 3 Fox news in March following the airing of a story on the First Call program by Fox reporter Sarah Cody
- We designed and sold awareness signs for display during National Down Syndrome Awareness Month
- The CDSC joined with other Ds groups in New England to support a booth at the American Congress of Obstetricians and Gynecologists (ACOG) conference that shared information with physicians. We provided funding and materials for distribution.
- The CDSC joined other Connecticut disability rights organizations in presenting a Disability Rights Candidate Forum at Manchester Community College
- Members of the CDSC board staffed information tables and represented the CDSC at events in Milford, Stonington and Berlin
- The CDSC joined the Central Connecticut Arc (CCARC) and Central Connecticut State University (CCSU) to co-sponsor a presentation by Brian Skotko
- With cooperation of the Aetna Corporation, we worked to raise Down syndrome awareness by lighting the cupola at the top of the Aetna headquarters building in Hartford blue and yellow during the month of October.

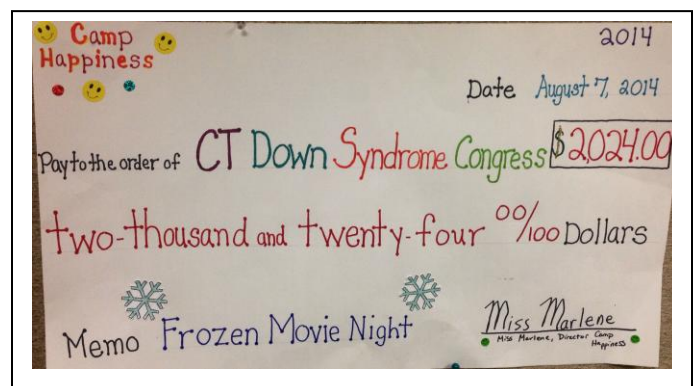


Special Thanks



Special thanks go out to Marlene Sanchez and our friends at Camp Happiness for a generous donation to a great cause.

For anyone interested in Camp Happiness next summer, applications go home with students after they return from April vacation next year. Parents may contact Director Marlene Sanchez at the Milford Recreation Department, 203-783-3280.



Exciting 2015 Programs & News

Bylaws Approved!

We are proud to announce that the Bylaws of the Organization were approved in 2014 and are now in place. This concludes a lengthy process undertaken by both the board of directors and Pro Bono Partnership. Thanks to all who voted.

Summer Camp Scholarships

We are happy to announce that four camp scholarships were issued in 2014. Congratulations to the camp scholarships recipients.

In 2015 we will be distributing annual grants of up to \$500 to help pay for overnight summer camp for individuals with Down syndrome. Applications are due by March 31st 2015. 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. You need not be present at the convention to receive the award. Email your application to campgrants@ctdownsyndrome.org.

Financial Audit

We are in the process of completing our 3rd Annual financial statement audit.

Based on the two prior years, and so far in 2014, we are happy to announce no internal control deficiencies and unqualified (clean) opinions for 2014, 2013 and 2012.



Our Board of Directors

President - Brian K. Morley bmorley@ctdownsyndrome.org

Vice President - Alan Llewelyn allewelyn@ctdownsyndrome.org

Secretary - Shanon McCormick smccormick@ctdownsyndrome.org

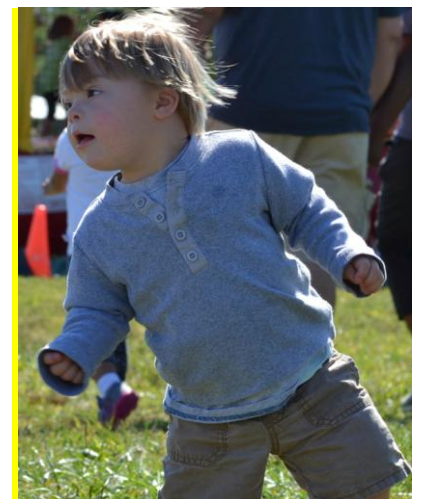
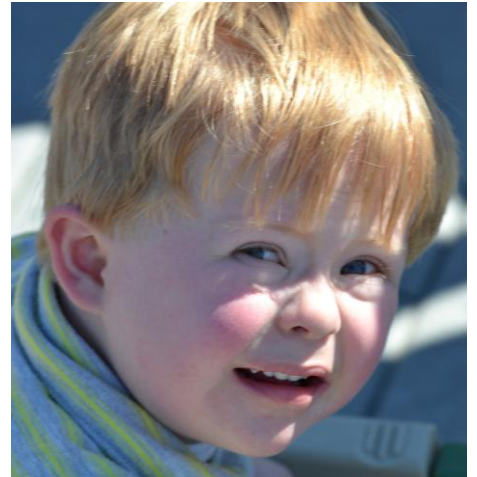
Treasurer - Ted Lucas tlucas@ctdownsyndrome.org

Director - Joseph Dennin jdennin@ctdownsyndrome.org

Director - Emily Kalenauskas ekalenuskas@ctdownsyndrome.org

Director - Harry Madler hmadler@ctdownsyndrome.org

First Call Coordinator – Patty Alessandro firstcall@ctdownsyndrome.org



A big thank you to our convention committee chairperson Laureen Morley and her committee members: Shanon McCormick, Patty Alessandro, Dominic Alessandro of AW-Design (www.aw-design.com), Emily Kalenauskas and Alan Llewelyn. Thanks also to the Water's Edge Resort.



Another big thank you for the invaluable legal services provided by Pro Bono Partnership on the CDSC's Amended Articles of Incorporation and bylaws. We recommend any not-for-profit organization in need of similar assistance contact the Pro Bono Hartford Team.