

cdsc

CONNECTICUT
down syndrome
CONGRESS



2015 Annual Report

November 7, 2015

Letter from Our Board of Directors

Dear Connecticut Down Syndrome Congress Member –

As president of the Connecticut Down Syndrome Congress and on behalf of your Board of Directors, I wish to welcome you to the 30th Annual Connecticut Down Syndrome Convention. We are delighted to once again be gathering at the lovely Water's Edge facility here in the scenic waterfront town of Westbrook, CT.

As usual the convention marks the end of my second favorite time of the year, no – not hockey season (Go Blackhawks!) or baseball season (Go Yankees!) or even the holiday season (Go Santa Claus?) but what I call “Down Syndrome” season (Go US!). It all begins each year with the mid-summer picnic when the Connecticut Down syndrome community gathers at Camp Harkness. As the summertime wanes, September arrives; bringing with it the start of school and our biggest fundraiser of the year, The Buddy Walk. And then comes today: the convention and our annual time of learning, sharing, and connecting with one another. The three events take place in a little over three months, leaving the rest of the year for opportunities to connect with the world, both typical and Down syndrome related as the year winds its way through the other seasons.

If you are with us for the first time, thanks for being here and connecting, this is 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 5, 10, 15, 20 or 30 times before -- this is your time to expand your horizons and explore that upcoming transition, your mission today is to **charge up**. So we have Down syndrome season at its end and an energetic group of people empowering themselves and connecting together, what are we to do next. . .

How do you take all of this energy and all of these feelings and channel it all into something long lasting? The answer is simple: do not stop, do not wait – look into your kids' eyes and realize that we can **never give up**. Opportunities for action abound, either at the statewide Board of Directors level or at the local level via one of the CDSC's county based groups. Take the connections you make today and put them to work year round. We have members in western Connecticut who connected with their Westchester, New York neighbors and founded a GiGi's Playhouse. There is a Fairfield county group called 21 Strong that every year hosts a statewide World Down Syndrome Day Awareness event at the YMCA down in New Canaan, CT. Creative Movement classes are going on in Hartford and Mom's Nights Out and playgroups are meeting around the state.

Enjoy your day here in Westbrook making connections at the convention and remember this message: whether it be Down syndrome season or not – **power up, charge up, never give up!**

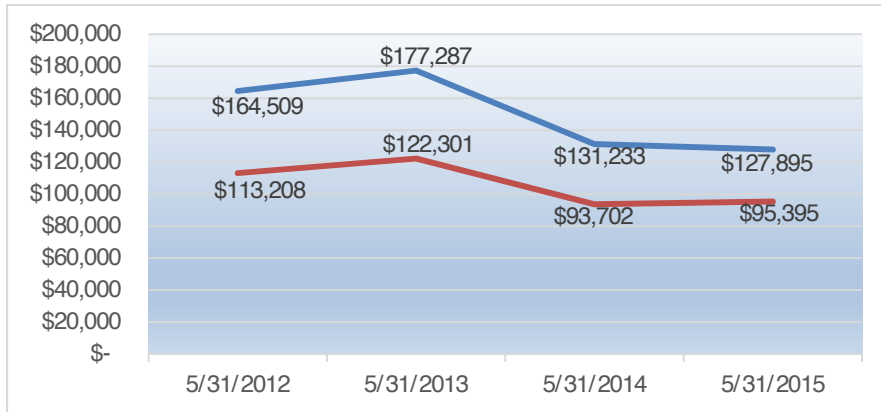
Sincerely,

Alan D. Llewelyn

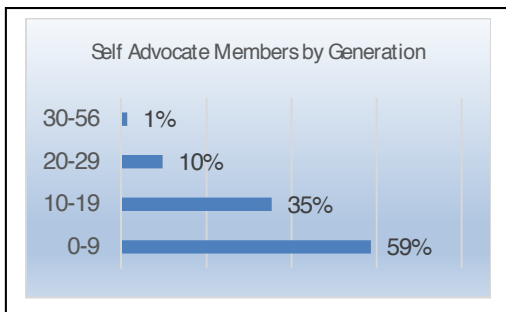
Alan D. Llewelyn, President – Board of Directors

2015 Highlights –Organization Statistics

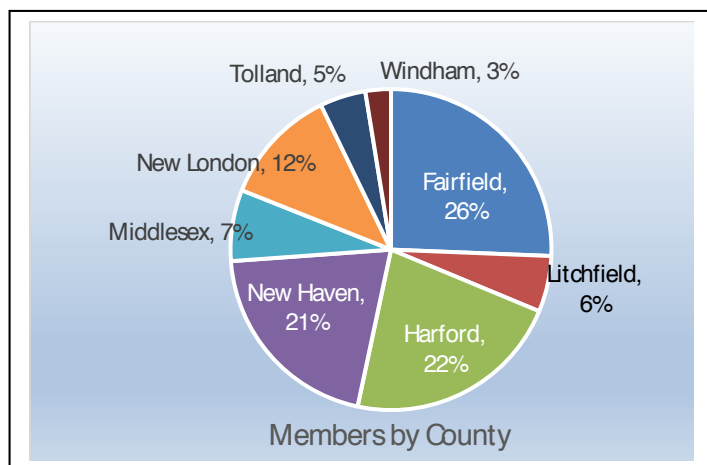
Revenues and Expenses by year: Changes in revenue are generally in line with our turnout at the Buddy walk and expenses generally coincide with revenues..



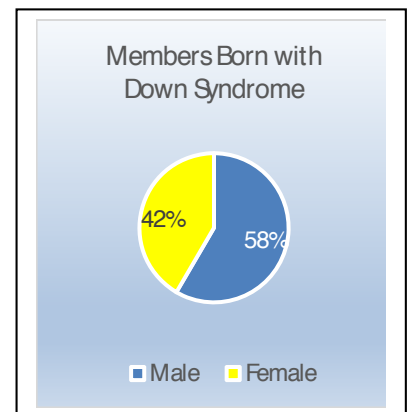
CDSC by the Numbers and More:



The Connecticut Down Syndrome Congress was incorporated in 1986 by a small group of parents concerned about the limited opportunities available to their children. Since that time, the CDSC has touched the lives of hundreds and even thousands across the state — people with Down syndrome, their parents, their siblings, their grandparents, friends and the people in their communities. Since 2008, when we began computerizing records, we have followed more than 500 individuals with Down syndrome and their families. While we’ve only got numbers at our fingertips for the last few years, we’ve been making a difference every day for the last three decades. We connect parents to one another, so they need never walk their path alone. We’ve joined with other disability



organizations to strengthen our voice in support of changes in education and social policy. We’ve shared best practices in education, medical and therapeutic intervention, so no child with Down syndrome is left behind. Finally, we’ve worked to change stereotypes to assure that every person with Down



syndrome is empowered as an individual and recognized for their accomplishments and contributions. The Connecticut Down syndrome Congress is a small organization by many measures, but we’re growing. We’re growing in numbers, we’re growing in influence and, most importantly, we’re growing in the kinds of support we offer. Today, the future for people who live with Down syndrome is brighter than it has ever been. The CDSC is proud to be a part of creating that future.

2015 Highlights – Advocacy: First Steps

First Steps is the CDSC's first effort to support our families with direct services and it is off to a great start.

Developing an appropriate Independent Education Plan (IEP) for a child with Down syndrome can be daunting. Parents need to develop a range of skills and knowledge to help their children be successful. For the past year, the CDSC has collaborated with the Connecticut Parent Advocacy Center (CPAC) to pilot First Steps -- a joint IEP training and mentoring program for CDSC members.

The first phase of the pilot study was completed in Hartford County in June. A CPAC staff member specifically trained in the Down syndrome learning profile worked one-to-one with CDSC member families to evaluate current IEPs and then train them in appropriate advocacy techniques through modeling and consultation. Parents learned about how to read the IEP as a legal document, how to identify sources of data and information and they learned how to prepare themselves for their meeting with teachers and administrators.

Six families were served directly through the program, and one topical workshop was presented. While the workshop on behavior was hosted through the First Steps program in Hartford County, it was open to CDSC members throughout Connecticut. Families who received individual mentoring through the CDSC First Steps program saved hundreds of dollars that they might otherwise have had to pay an advocate for similar training.

In a survey at the end of the first year, parents in Hartford County reported being very satisfied with the program and the support it provided. In September 2015, the CDSC board of directors voted to expand the program to Litchfield County, with an eye toward further expansion and enhancement of the program in coming years.



“It [the First Steps Program] gave me more confidence and made me feel like I was really part of the team and not an outsider at the PPT meeting” - First Steps Parent

2015 Highlights – First Call Program (Year 3)

The CDSC First Call Program is 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, took over the program a little over three years ago as 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.





2015 Highlights – 12th Annual Buddywalk



Congratulations to our 2015 Buddy Walk top teams:

1. Team PRO Captain: Mike O'Rourke



2. Grace's Gang Captain: Guisela Lombardo



3. Charlotte's Angels Captain: Lisa Thygerson



Thank You to Our 2015 Buddy Walk Sponsors



aetna MARCUM



Financial Audit

We have successfully completed our 4th Annual financial statement audit. We are happy to announce that we have received an unqualified (clean) opinion as of and for the year ended May 31, 2015.

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


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2015 Highlights – Strategic Planning

In 2015, the CDSC board of directors embarked on strategic planning. We hired Association Resources, a West Hartford-based consulting and managerial support firm, to help us. Of the numerous ideas and directions discussed, the board committed to the following short and long-term goals:

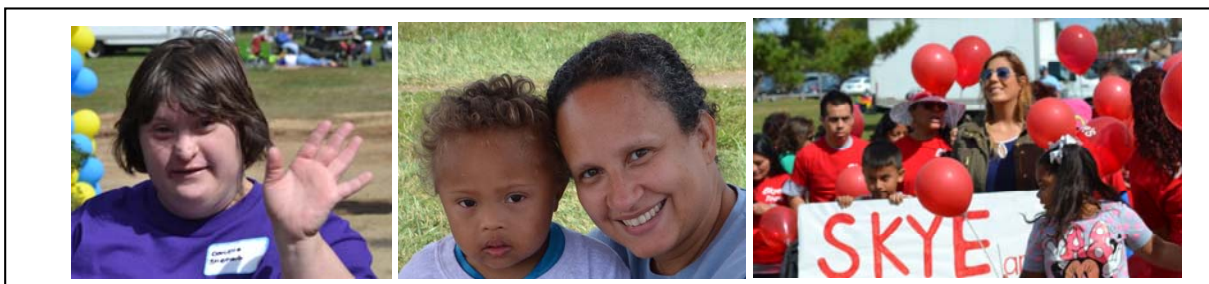
Short-term Goals:

<u>Goal:</u>	<u>Description</u>	<u>Progress</u>
Enhance the CDSC Brand	Update Logo, website, promotional materials	Ongoing – STAY TUNED!
Enhance events through partnerships	Enhance fundraising and event planning by contracting for necessary services	Ongoing- Use of AR for 2015 Convention

Long-term goals:

<u>Goal:</u>	<u>Description</u>	<u>Progress</u>
Establish a facility	Facility will serve as a meeting place for members and the home for a Ds Educational Resource and training center	Long-term goal
Achieve passage of the Connecticut Down Syndrome Information Act	Lobby for this Act	Long-term goal

A special thank you to Chip Marsh, Executive Vice President, Association Resources!



2015: Events Recap – Summer Picnic

The CDSC had our annual summer picnic for members on Saturday July 25, 2015 at Camp Harkness in Waterford, CT. It was a beautiful summer day, enjoyed by all who attended. There was a catered lunch, music by the White-eyed Lizards, along with access to the beach and playground. Families brought their sand toys, kites and swimsuits and had a great time. The annual picnic is always a great opportunity to connect with other CDSC families and make new friends.



2015: Events Recap – Convention

The CDSC held its 29th Annual Convention on November 8th, 2014 at the Water's Edge Resort in Westbrook, Connecticut.

Sara Wolff is an incredible young woman and a very gifted inspirational speaker who has spoken to many audiences over the past years on her views of Down Syndrome advocacy, living with disability and overcoming adversity. At the 2014 convention, she spoke of her life experience with Down Syndrome, and how her work with The National Down Syndrome Society has given her the insight to understand and address a wide variety of subject matters.



Camp Grants

The second year of the CDSC camp scholarship program was very successful. We had 10 applications for scholarships and offered all 10 applicants grants ranging in amounts from \$150 to \$500. The grants can be used for either day camps or overnight camps. We see the grants as one of the tangible benefits of belonging to the CDSC.



"We would like to thank you very much for the Camp Grant which was given for our son Benjamin to attend the I Can Bike Camp this summer. He went from having no bike riding experience, to making amazing progress towards riding his bike almost independently in just one week! This was an incredible experience for our family, and we are so grateful. This camp gave him so much confidence and it was so thrilling to see him do so well and be so proud of himself and his accomplishment! This camp was one of the highlights of our summer!" Ernie and Laurie Cantwell



"My heart is overwhelmed and humbled by the grant the CDSC offered my children, Marshall and Michael, to attend Camp Happiness in Milford this summer. I found the check from the City of Milford in my mailbox yesterday, and I was once again assured of the joyful community that I am so privileged to be a part of. I continue to see obvious and not so obvious signs of wholeness in my life as my husband and I raise our two sons who have Down syndrome. We can only be successful in this with the incredible support from wonderful people and active associations such as CDSC. I really believe that "it takes a village". I would like to share that Michael, who is barely able to walk at 8 years old, actually jumped off the diving board 3 times the other day at Camp Happiness!!! Marlene Sanchez and her team of counsellors are so very amazing!" Holly Firmender

Like 2015, in 2016 we will be distributing annual grants of up to \$500 to help pay for overnight summer camp for individuals with Down syndrome. Applications are accepted on a rolling basis for overnight camp, beginning March 1st. If funds remain, the program is opened to day camp applicants on May 1st and continues through the end of our fiscal year, May 31st, or until budgeted funds are exhausted. 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.

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

Director - Joseph Dennin jdennin@ctdownsyndrome.org

Director - Emily Kalenauskas ekalenauskas@ctdownsyndrome.org

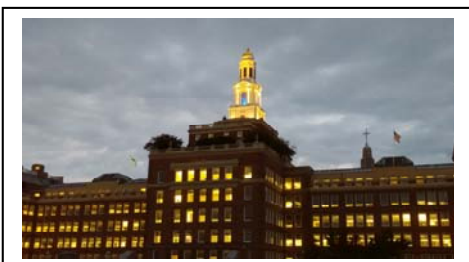
Director – Laurie Cantwell lcantwell@ctdownsyndrome.org

Past President – Brian K. Morley bmorley@ctdownsyndrome.org

First Call Coordinator – Patty Alessandro firstcall@ctdownsyndrome.org



A big thank you to our convention committee members: Laureen Morley, Shanon McCormick, Patty Alessandro, and Emily Kalenauskas. And to the Water's Edge Resort.



Our friends at Aetna Insurance lit the cupola of their headquarters in Hartford in blue and yellow for Down syndrome Awareness Month in October. Our growing relationship with Aetna is just one of many the CDSC is establishing with businesses in Connecticut to help us fulfill our mission.

