2016 ANNUAL REPORT

BUILDING AN INCLUSIVE FUTURE
WE CAN ALL BELIEVE IN
Thanks to your support, the MDSC made a significant impact in the lives of people with Down syndrome and their families across the Commonwealth in 2016.

We advanced a wide range of initiatives to create more opportunities for people with Down syndrome to live meaningful, fulfilling lives throughout the lifespan.

Over the last 12 months we worked on everything from making systemic changes in disability policy to providing critical programs for individuals with Down syndrome and their families.

We passed another major piece of legislation - our Organ Transplant Non-Discrimination Bill - which once and for all guarantees that people with Down syndrome and other disabilities are not arbitrarily passed over when waiting in line for critical, life-saving procedures.

Our Your Next Star employment campaign made significant inroads in the hiring landscape in Massachusetts through meetings with 125 employers who learned about the benefits of hiring a diverse workforce.

We continue to expand our bedrock Parents First Call program by expanding our personalized services to meet the needs of families including: baby massage and sign language classes; support groups for Spanish-speaking families and families of diverse backgrounds; our Dads Appreciating Down Syndrome (DADS) Affiliate gatherings; New Family Socials, Grandparents Get Togethers and our first ever “Families with Twins Social.” We give special attention to our families with loved ones with special health care needs, including hosting a Complex Needs Support Group, and hosting monthly chats for families through our Down Syndrome Autism Connection Affiliate.

In 2016, we expanded offerings and explored new territory throughout our signature Advocates in Motion (AIM) Initiatives. AIM youth delved deeply into a Presenting Myself to the World theme, which was carried through monthly AIM Hangouts, AIM Parent Meetings and AIM Socials. Our 16-member Self Advocate Advisory Council (SAAC) planned events for adult peers and took on new projects, like publishing its very first newsletter, written by and for adults with Down syndrome. And, AIM and SAAC collaborated with PricewaterhouseCoopers on a 4-part financial literacy series.

Our cutting edge webinars and expert-packed conferences gave teachers and parents the best practices and strategies they need to foster inclusive, forward-thinking educational environments. Our 12th Educators Forum in November was over-subscribed with 375 attendees and our Educator’s Guide has sold over 1,200 copies nationwide.

On Oct. 9, 2016, we celebrated 20 years of our signature Buddy Walk & Family Festival in Wakefield which is one of the largest Down syndrome awareness events in the nation. And our regional walks - the Buddy Walk by the Sea and Buddy Walk Harvest Fair - both moved to new locations and saw tremendous growth that bodes well for the future of our community throughout the state.
The Board of Directors approved a 5-year Strategic Plan that provides an ambitious blueprint for the MDSC through 2020 got off to a strong start in 2016, laying the groundwork for the work ahead. Now, in 2017, our Management Team is delving into the plan, working on directives that will expand our resources, programs and advocacy. We’re designing a program and services model to serve individuals and families across the lifespan; build a community that fosters and sustains a sense of belonging; and increase capacity to ensure that the MDSC has a sustainable financial foundation for the future.

The MDSC is committed to ensuring that families and individuals with Down syndrome have the local supports and resources they need. And, for the past four years, we have brought together more than two dozen leaders in the Down syndrome community from across the state for our annual Support Group Leader Retreat. These groups play an integral role on the local level welcoming MDSC members and supporting them on a very personal level - meeting families face-to-face, developing meaningful relationships, and sharing information and resources. The retreat continues to be a significant event for fostering close collaboration to best meet the needs of families.

Having made statewide advocacy a hallmark in recent years, the MDSC has established itself as a leader in disability policy. Already, we have led the efforts to pass critical pieces of legislation that are changing lives for the better- the Down Syndrome Information Act, Real Lives Bill, National Background Check Bill, the ABLE Act, and the most recently passed Organ Transplant Bill.

A critical element of our legislative success has been connecting with legislators, sharing our personal stories and challenges. And one of the most effective vehicles for doing this has been through our annual Down Syndrome Advocacy Day at the State House. In 2017, we will hold our 4th Annual Advocacy Day, once again at the Grand Staircase of the State House.

So many of you, in your own individual way, have helped the MDSC achieve our mission in 2016. Working together, we have had a tremendous impact.

Whether you served in a leadership role, significantly contributed to one of our walks, hosted a community fundraiser, made a contribution to one of our many programs, funded a grant to make our work possible, or joined us at one of our many events, we salute you for your support.

In closing, we look forward to an exciting journey with you in 2017 with more opportunities for our community than ever before. Thank you for all you have done to make the MDSC what it is today.

Your leadership and support is truly valued and appreciated.

Maureen Gallagher, MS
Executive Director
Massachusetts Down Syndrome Congress

Jud DeCew, PhD
Board Chair
Massachusetts Down Syndrome Congress
ABOUT THE MDSC

The Massachusetts Down Syndrome Congress (MDSC), established in 1983, began as a non-profit organization made up of parents, professionals and anyone interested in gaining a better understanding of Down syndrome. Its roots trace back to a group of parents, in a living room in 1983, chatting about their children with Down syndrome and how they could connect and educate families, schools and communities. Thirty years later, with over 5,000 members, the MDSC has an energetic Board of Directors, a dynamic management team, and a vision to ensure that every person with Down syndrome has the opportunity to reach their full potential.

MISSION STATEMENT

To ensure that individuals with Down syndrome in Massachusetts are valued, included, and given the opportunities to pursue fulfilling lives by providing information, networking opportunities, and advocacy for people with Down syndrome and their families, educators, health care professionals, and the community-at-large.

OUR VISION

The MDSC wants to be recognized by people with Down syndrome and their families, educators, health care professionals, and the community-at-large as the preeminent organization in Massachusetts for information, networking, and advocacy for and about Down syndrome.

OUR PURPOSES

- To better educate the public in Massachusetts about the possibilities and potential of all people with Down syndrome throughout their lifetime.
- To enable networking, social/friendship opportunities and direct supports for all people with Down syndrome and their families throughout Massachusetts.
- To advocate that all individuals with Down syndrome in Massachusetts have high quality education, which includes transition planning and life-long learning.
- To educate our stakeholders through a clearinghouse of information and resources related to Down syndrome including best evidence-based practices in Massachusetts.
- To ensure that expectant and new families receive accurate and up-to-date information and desired supports.
- To empower all people with Down syndrome to become effective self-advocates.
- To advocate for improved systemic change and policy in issues such as community inclusion and employment for adults with Down syndrome.
- To advocate for all individuals with Down syndrome to have access to high quality medical services and research.

Cover Photo by disabilityimages.com
Every year for the past several years, the MDSC has chosen a theme that represents where our Down syndrome community is, and where we’re going. In 2015 it was “The World Is Ours.” In 2014, it was “Champions.” And in 2013 “Real Lives.”

For 2016, we were proud to focus on the new theme – “BELIEVE”!!! The concept of believing relates to virtually everything we do.

We BELIEVE that people with Down syndrome should be allowed to pursue meaningful lives in their communities. We BELIEVE that all aspects of society should accept and include individuals with Down syndrome fully. We BELIEVE that new and expectant parents should have access to the latest, most accurate information about having and raising a child with Down syndrome. We BELIEVE that people with Down syndrome should not be defined by their disabilities, but rather should be celebrated for their abilities.

We BELIEVE that people with Down syndrome deserve every opportunity for an education that truly meets their needs, a good job that allows them to earn money, quality healthcare that doesn’t discriminate and a fulfilling social life. Ultimately, we BELIEVE that each person with Down syndrome should be honored as the individual he or she is and for the immeasurable value they bring to the world.

We BELIEVE in the future of all people with Down syndrome and pledge to do everything in our power to ensure that they have the opportunities they so richly deserve.
2016 FINANCIAL STATEMENT
Connecting Revenue with Expenses
For Fiscal Year Ending June 30, 2016

REVENUE
Total Revenue $1,381,500

EXPENSES
Total Expenses: $1,498,800

For more detailed financial information, please contact us at mdsc@mdsc.org.
PARENTS FIRST CALL
Energizing New Families About the Journey Ahead

The last thing on Tim and Shu Talun’s minds when they were pregnant with their second son was the 1 in 830 chance of having a child with Down syndrome.

So in late 2015, when the Somerville family got a prenatal diagnosis, they were initially thrown for a loop. But before long, they were thrown something else, what Shu calls “a lifeline” - in the form of the MDSC’s Parents First Call Program. “Immediately, they provided support and helped us adjust to our new reality,” Shu says.

“The MDSC helped us understand what Down syndrome is and connected us to a network of people willing to share their own experiences.”
– Shu Talun

Tim and Shu attended one of the MDSC’s first pre-natal social get togethers. “They helped us understand what Down syndrome is and connected us to a network of people who were more than willing to share their own experiences and provide us with guidance.”

Knowing their son would need heart surgery soon after birth, they gave their newborn the name Lewis, meaning “renowned warrior,” continued to connect with the MDSC for support and guidance, and, feeling the need to give back right away, set up a Buddy Walk team to raise funds and promote awareness.

“The friendships we made through resources and events have brought us comfort and joy,” Shu says. “We are grateful to be a part of this loving community and are comforted knowing the MDSC will continue to support us though future challenges.”

In 2016, we have continued to expand our bedrock Parents First Call program, expanding our personalized services and meeting families “where they’re at” - baby massage and sign language classes; support groups for Spanish-speaking families and families of diverse backgrounds; our Dads Appreciating Down Syndrome (DADS) Affiliate gatherings; New Family Socials, Grandparents Get Togethers and our first ever “Families with Twins Social.”

We have given special attention to our families with loved ones with special health care needs, including hosting a Complex Needs Support Group (with Children’s Hospital Boston), and hosting monthly chats for families through our Down Syndrome Autism Connection Affiliate.

It’s no wonder our First Call Program is a national and international model for how to ensure that new and expectant parents get all the support and guidance they need – one family at a time.
172 new and expectant families received personal one-on-one support, information and guidance from our First Call Program in 2016.
When Steve Narey visits his 11-year-old’s classroom, the Williamstown attorney is thrilled to see a teacher and elementary school committed to creating a fully inclusive experience for his son Cole. But he also sees something more - the critical role the MDSC has played laying the groundwork for best practices that are being implemented for Cole and hundreds of others with Down syndrome in schools across Massachusetts.

“I have a great deal of admiration for those who advocated to get us where we are today," says Steve. “Without their work, there would be no IDEA and ‘Least Restrictive Environment’. Cole would be in a substantially separate classroom.”

In fact, Steve’s respect for the work of the MDSC compelled him to take up the mantle of earlier pioneers. He joined our Board of Directors and took particular interest in our public policy efforts. Now, he had an opportunity to play a role himself driving our legislative agenda forward.

During his tenure as Chair of the Board, Steve was able to see, and participate, as the MDSC passed several landmark laws that would help Cole in important ways - like the National Background Check Bill and Real Lives Bill. In 2014, the MDSC launched our Down Syndrome Advocacy Day at the State House, now an important annual event. And, Steve has been part of our MDSC delegation for the NDSS Buddy Walk on Washington, where we lobby legislators on Capitol Hill.

“The MDSC is changing policy at the local, state and federal level,” Steve says. “It’s allowing people with disabilities to exercise control over their lives and have opportunities to reach their full potential.”

The MDSC’s policy successes over the last 5 years - the Down Syndrome Information Act, Real Lives Bill, and National Background Check Bill - have undeniably changed lives for the better.

That’s why in 2016, we continued to make statewide advocacy a hallmark, pushing two new critically important priority bills. The Higher Education Opportunities Bill would open doors to a college education long closed to people with disabilities. The Organ Transplant Bill would prevent medical professionals from discriminating against people with disabilities when deciding who gets life-saving medical transplantations. (It eventually passed in late 2016.)

We celebrated our 3rd Annual Advocacy Day at the State House, which has become a prime venue for connecting with legislators and sharing our personal stories and challenges.
225 people attended our Buddy walk on Washington and Down Syndrome Advocacy Day, taking action to create systemic change.
In 2012, the MDSC held the first ever Northeast Down Syndrome Educators Conference in Burlington, Mass., playing host to our British counterparts at Down Syndrome Education International. For Mychelle Lee, whose daughter Allyson was not yet 2, it was her first taste of the educational resources and best practices available to her and other families through the MDSC.

“I learned so much. It was the flame that ignited everything,” she says. “I took some things home with me. I started researching other things. It was a cascading event.”

Indeed, since then, Mychelle has benefited from the full range of MDSC education resources - Early Education Workshops, our Meaningful Inclusion for Students with Down Syndrome Educators Manual, networking with other MDSC parents and consulting directly with MDSC staff about her daughter’s IEP.

Mychelle describes exposure to MDSC educational resources as having lasting “ripple effects” - information that is not only valuable at the time, but that she delves deeply into online later, that she uses with her other children (who do not have Down syndrome), or that Allyson’s teachers can extrapolate for the rest of the class.

In 2015, Mychelle sent Allyson’s preschool teacher to our Annual Educator’s Forum, and saw the same dynamic. “Her teacher soaked up the information there, shared it with her colleagues, and they were able to use it immediately, even with other ‘typical’ kids in her class,” Mychelle says. She is thankful that the MDSC has the education expertise to help her family as well as so many others.
General and special educators, paraprofessionals, administrators, specialists and parents learned best practices in educating students with Down syndrome through MDSC webinars, workshops and our three major conferences - the Educators Forum, the Annual Conference, and the Adult Conference.
Karen and Charlie Gadbois have been integrally involved in the MDSC since their daughter was born 20 years ago, well before the MDSC’s signature Advocates in Motion Program was even created. Still, their trust and confidence in the MDSC couldn’t entirely allay their concerns when they signed Marie up for AIM two years ago. After all, they’re parents.

Marie had done lots of other community activities - like dance or sports - but they were always very structured. “It was ‘do the activity’ then go home,” Karen says, “AIM is more like hanging out. I wasn’t sure she’d be able to do it.”

To start, Marie was teamed with a longtime volunteer as her parents watched from a distance. But the extra supports became mostly superfluous. Almost before Karen and Charlie could ask “Would she fit in? Make new friends? Enjoy herself?”, their fears were allayed.

Today, Marie is not just comfortable at AIM, she becomes ecstatic when AIM weekends roll around. “She’s never been in a program with so much independence,” Karen says. “She takes pride in hanging out with peers.”

Karen points out that the arrangement has benefits for parents too, as she and Charlie have gained a couple of precious hours on certain Sundays.

“She’s never been in a program with so much independence. She takes pride in hanging out with peers.”

– Karen Gadbois

In 2016, the MDSC’s A.I.M. Teen & Young Adult Program expanded offerings and explored new territory while providing fun, challenging, educational programming for nearly 200 teens and young adults from 13 to 22. AIM youth delved deeply into a Presenting Myself to the World theme, which was carried through monthly AIM Hangouts, AIM Parent Meetings and AIM Socials.

Participants developed leadership and self-advocacy skills, formed meaningful relationships, and built self-confidence, not to mention having fun with dance, yoga and sports, and at events like their annual Halloween and holiday parties.

191 self advocates between 13 and 22 gained leadership skills, life skills, and made friends in our Advocates in Motion Program.
Recognizing that people with Down syndrome should have every opportunity to lead inclusive fulfilling lives in the community, the MDSC has made public awareness a top priority. In 2016, we celebrated 20 years of our signature Buddy Walk & Family Festival in Wakefield. Other public awareness and fundraising initiatives that MDSC members participate in include the Boston Marathon and Falmouth Road Race as well as our beloved annual Hockey Game with the Boston Bruins Alumni. We know that by working together to engage our community we can educate others about the immeasurable value all people with Down syndrome bring to the world.

Danielle Thompson’s journey began right after the birth of her first child four years ago when her son, Drew, was born with Down syndrome. Instead of allowing herself to stress, Danielle did what came naturally – she simply “focused on my beautiful baby boy, knowing deep down everything would be okay.” She couldn’t have been more right.

“Knowing the MDSC and our community has our backs means the world to us.”
– Danielle Thompson

Within days, Danielle was connected to the MDSC, and upon arriving home, she received a welcome package with a congratulatory letter, a warm blanket and the MDSC’s informative and reassuring newsletter. “At the time, just knowing the MDSC community existed was comfort in itself,” Danielle says. “I immediately knew these were my people.”

It wasn’t long before Danielle realized she wanted to get involved in MDSC’s signature awareness program, the Buddy Walk and Family Festival. She started a team called Drew’s Crew and worked hard with family and friends to spread the word about her campaign to make a difference in the lives of individuals with Down syndrome.

Drew was just two in the spring of 2015 when, as one of the MDSC’s top team captains, Danielle stepped up to become Co-Chair of the Buddy Walk & Family Festival. Over the next two years, she worked tirelessly to help plan and strategize the event, motivate the Buddy Walk Task Force, and spread our message of empowerment far and wide – appearing in two FOX25 public service announcements, recording interviews on Mix 104.1 radio and getting the word out all over social media.

And Danielle knows exactly why she’s doing it all. “Our family has already discovered just how critical the MDSC’s programs and educational initiatives are,” says Danielle. “Knowing the MDSC and our community has our backs means the world to us!”

Through Danielle’s efforts and that of so many other dedicated volunteers, the MDSC Buddy Walk program has grown to three Buddy Walks statewide and is the largest public awareness platform for Down Syndrome in New England.
4,525 families, self advocates and friends came together at our Buddy walks and other awareness and fundraising events to celebrate the lives of people with Down syndrome.
Every year, Professor Shoumita Dasgupta of the Boston University School of Medicine asks the MDSC to bring a panel of experts to visit her Genomic Medicine class Principles Integrating Science & Medicine.

MDSC embraces these kinds of medical outreach requests because we know how critical it is to ensure that medical providers clearly understand and are sensitive to the needs of individuals with Down syndrome and their families.

The panel, comprised of a parent, self-advocate and a physician, speaks to the class about the facts but also emphasizes that each person with Down syndrome is unique and should never be defined by their extra chromosome. “Your visit is so impactful,” Professor Dasgupta wrote after a recent visit. “It really helps the students ask themselves about the kind of doctors they would like to grow to be.”

Inevitably, most of the nearly 200 first-year medical students - so accustomed to being analytical and empirical - are completely awestruck by what they learn, as recorded on index cards that Professor Dasgupta collects from each student after class.

“My thoughts, feelings, and approach to dealing with genetic conditions in my personal and professional life will forever benefit from these sessions.”
– BU Medical student

“I was scared of genetic [conditions] prior to starting medicine,” one wrote. “I did not know their true impact. I have been completely proven wrong, and my thoughts, feelings, and approach to dealing with genetic conditions in my personal and professional life will forever benefit from these sessions.”

“In my future interactions with my patients and their families,” another wrote, “rather than being their judge or decision-maker, I will instead try to seek an understanding of their story so that I can partner with them on their journey ahead. Life is a journey, a diagnosis is a journey, our relationship is a journey; more than anything else, it is an honor and privilege to be on it with them.”

At the MDSC, we understand the promise and pitfalls of scientific innovations and strive to provide all the support and guidance our members need to make informed decisions.
741 Healthcare professionals received up-to-date accurate information about Down syndrome through MDSC medical outreach programs.
SELF ADVOCATE ADVISORY COUNCIL & ALLEN CROCKER INTERNSHIP

Igniting the Confidence Inside All of Us

On Felicia Patti’s application for the MDSC’s Allen Crocker Self Advocate Internship, she wrote that she “would love more opportunities to speak in public, speak up for my rights and also get real office working experience.”

As the Crocker Intern Program is designed to allow participants to work on projects of their choosing, that’s exactly what Felicia did during her tenure in the winter of 2015/2016. She addressed undergraduate students at UMASS Amherst, spoke to runners and families at the MDSC Boston Marathon Luncheon, represented the MDSC at check presentation ceremonies, and co-led an advocacy mini-workshop at our 32nd Annual Conference.

“It was the biggest thing that ever happened to her, and her confidence has skyrocketed.”

– Patrice Patti

It didn’t take long to realize there was something else that really excited Felicia – acting. “I would like to eventually be on TV,” she said. With this, the MDSC sprang into action, reaching out to a Los Angeles talent agency, and eventually scoring an audition for her on the ABC docu-series “What Would You Do?” in New York City.

“It was the biggest thing that ever happened to her,” says her mom, “and her confidence has skyrocketed.” In the wake of her internship, Felicia started taking acting classes in Woburn, began a new job at a cafe in North Reading, and joined the MDSC Self Advocate Advisory Council, where she is flourishing.

Her mom notes that in some ways, her daughter is a different person today. “Felicia doesn’t blink an eye speaking in front of people anymore,” which she did off-the-cuff at their family Christmas party. And Felicia’s confidence that her Hollywood dreams will come true remains strong. “Nobody is going to tell her that she’s not going to be an actress.”

Our Crocker Internship and Self Advocate Advisory Council (SAAC) give self advocates like Felicia opportunities to drive the MDSC mission, connect and lead. Our expanded 16-member SAAC advise the MDSC Management Team on issues of importance to self advocates and work hard to create a better life for themselves and others.

In 2016, they planned events for adult peers and took on new projects, like publishing their very first newsletter, written by and for adults with Down syndrome. And our SAAC group began a new collaboration with PricewaterhouseCoopers on a 4-part financial literacy series that is preparing our loved ones for the future.
119 adults with Down syndrome participated in leadership activities and joined the new networking and socializing events organized by self advocates for self advocates.
EMPLOYMENT

Changing the employment landscape for people with disabilities

In March 2016, at the DCU Center in Worcester, Philip Donahue presented Market Basket and the company’s president, Arthur T. Demoulas, with the MDSC’s first-ever Employer of the Year Award.

Fighting back tears, Phil explained just how much his job has meant to him. “I was 16 years old when I started working at Market Basket,” he said. “I’ve worked other places over the years, but Market Basket is my favorite. They are like family to me.”

Phil’s employment story is remarkable. Having worked his way up from bagger to Customer Service Representative over 20 years - even going on strike for the company three years ago - his loyalty is unmatched. But in other ways, his story is entirely typical. The fact is that people with Down syndrome are often among the most dedicated, reliable, honest, hard-working employees around.

That’s why we built our Your Next Star employment campaign. By sharing the real-life employment stories of Phil and many others, and providing information, tools, tips, and resources related to hiring people with intellectual/developmental disabilities, we are educating and inspiring employers about the contributions people with Down syndrome make to the workforce.

And building on our employment campaign’s success, we are partnering with the state’s Regional Employment Collaboratives to host “Diversify Your Workforce” forums around the state. These forums introduce employers to the benefits of diversifying their workforce and give them guidelines on how to find qualified candidates with intellectual/developmental disabilities who are ready and willing to work.

Since its launch in October 2015, the Your Next Star web portal and public awareness campaign – www.yournextstar.com – is already making major inroads into the employment landscape for people with Down syndrome and other disabilities in Massachusetts. The innovative, interactive initiative has garnered attention from the likes of FoxNews and the Boston Globe, and has been viewed, shared and visited more than 25,000 times online.

Our Diversify Your Workforce outreach forums are making their way around the state educating and inspiring employers. Each one features a panel of speakers including model employers, an employment law attorney, state legislators and a self advocate who is competitively employed.

Because of the campaign, we have had audiences with the likes of FedEx, Brueggers Bagels, Home Depot, MIT and Babson College, and are literally changing the employment landscape for people with disabilities in Massachusetts.

People with Down syndrome are often among the most dedicated, reliable, honest, hard-working employees around.
1,450 employers, human resource professionals, partners and others reached through in-person presentations of the Your Next Star employment campaign.
MDSC LEADERSHIP

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