Creating Life-Changing Opportunities for 35 Years and Counting
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 2017.

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 continue to expand our nationally recognized Parents First Call Program by broadening our support services to meet the needs of families. This year we launched our new MDSC Cares Program that offers hospital visits and care packages for families whose child is experiencing an extended hospital stay. We started a new playgroup specifically for parents of children with Down syndrome ages 4 to 7. For single mothers, we began a new support group designed to meet their unique needs. All these new initiatives, along with our many other support programs, are aimed at ensuring that all families have the critical supports they need during the early years.

As children approach school age, we are right there with our families providing important education resources as their children transition to school. We piloted a Resource Parent Volunteer Program, which delivers one-on-one support to MDSC families seeking education-related resources and guidance. Participants are matched with an experienced parent mentor who guides them with practical education tips and useful information.

We launched Accept the Challenge (ATC), a new education-focused awareness program designed to promote understanding and acceptance of each other, regardless of differences and challenges. Building an inclusive community is an ever-evolving process that requires ongoing, honest, and supportive learning opportunities and conversations designed to highlight the fact that universally, we all have different strengths and confront different challenges. This program has been presented in a variety of schools that have expressed a desire to build an inclusive, welcoming school environment.

The MDSC’s self-published education manual, Meaningful Inclusion for Students with Down Syndrome – A Resource Guide for Elementary Educators continues to make waves in the Down syndrome and disability education space. With over 2,600 copies sold, this essential guide for special education teachers and parents has had a tremendous impact here in Massachusetts and beyond.

Our self advocates with Down syndrome are central to everything we do at the MDSC, so it should be no surprise that our Self Advocate Programs continue to be an essential part of our programming.

Our signature Advocates in Motion (AIM) Program, is exploring their theme for the year, Together we CAN. They are getting out in to the community, working as a team, and learning about how to make the world a better place!

Our Self Advocate Advisory Council for adults with Down syndrome hosts quarterly socials that provide opportunities for people to enjoy time with friends.
In addition to our Annual Conference and Educators Forum, we host a conference exclusively for adults with Down syndrome, their family members and support providers. In collaboration with the MGH Down Syndrome Program this conference focuses on empowering adults and their families to plan for a longer, healthier and more meaningful future.

Our Your Next Star Employment Campaign, now beginning its third year, continues to make significant inroads in the hiring landscape in Massachusetts. Through our regional Diversify Your Workforce events, we’ve reached over 200 employers who are learning how to open doors to include more individuals with Down syndrome in their workplace.

Our Buddy Walk Program now boasts three walks around the state, each with its own unique personality - the Buddy Walk by the Sea in Hyannis, Buddy Walk & Harvest Fair in Westborough and Buddy Walk & Family Festival in Wakefield.

In 2017, we had our most successful Buddy Walk season yet, with record-breaking fundraising results. But perhaps even more importantly, we took our awareness efforts to a new level, not only in the local communities where the walks were held, but across the state. We celebrated an important anniversary – 21 years of our Buddy Walk Program – with a 21 Campaign on social media and a very special guest at our Buddy Walk & Family Festival, Governor Charlie Baker.

Having made statewide advocacy a hallmark over the last 6 years, the MDSC has established itself as a leader in disability policy, helping move legislation that is changing lives - the Down Syndrome Information Act, Real Lives Bill, National Background Check Bill, and the 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 2018, we will hold our 5th Annual Advocacy Day, once again at the Grand Staircase of the State House on May 31st.

Our 5-year Strategic Plan, which provides an ambitious blueprint for the MDSC through 2020, continues to guide us in expanding our reach to serve more individuals and their families than ever before. Now, in 2018, our Management Team is delving into the plan, working on directives that will expand our resources, programs and advocacy. By designing a state of the art program-and-services model, we will be able 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.

So many of you, in your own individual way, have helped the MDSC achieve our mission in 2017. 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, or funded a grant to make our work possible, we salute you for your support.

In closing, we look forward to an exciting journey with you in 2018 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-five 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 educate our stakeholders through a clearinghouse of information and resources related to Down syndrome including best evidence-based practices in Massachusetts.
- 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 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 ensure that expectant and new families receive accurate and up-to-date information and desired supports.
- To advocate for all individuals with Down syndrome to have access to high quality medical services and research.
Every year, the MDSC chooses a theme that represents where our Down syndrome community is, and where we’re going. In 2016, it was “Believe.” In 2015, “The World Is Ours.” In 2014, it was “Champions.” And in 2013 “Real Lives.”

For 2017, our theme projected a powerful message from each and every one of our loved ones with Down syndrome and their families - “COUNT ME IN”!!

By declaring “Count Me In,” we are raising our hands as individuals and as a community to say, “Don’t forget about us!” But as much as we’re asking our schools, our neighbors, our media, our places of employment, and our government to be thoughtful and inclusive institutions, we’re also demanding that they do so!

For 35 years, the MDSC has been creating life-changing opportunities for people with Down syndrome. Our community includes individuals with the full spectrum of interests and abilities, people of all different cultures and backgrounds, individuals with unique viewpoints and personalities. What ties us together? Ultimately, all people with Down syndrome and their families want to be COUNTED and deserve to be INCLUDED.

We are positive. We are diverse. We are accepting. And together, we are helping the world understand the math that really COUNTS - that the 3rd copy of the 21st chromosome that defines Down syndrome adds up to a better world for everyone. So COUNT US IN!
2017 FINANCIAL STATEMENT
Connecting Revenue with Expenses
For Fiscal Year Ending June 30, 2017

REVENUE
Total Revenue $1,661,515

EXPENSES
Total Expenses: $1,585,172

For more detailed financial information, please contact us at mdsc@mdsc.org.
In 2017, we continued to expand our nationally recognized Parents First Call Program by augmenting our support services to meet the needs of families. We launched our new MDSC Cares Program that offers hospital visits and care packages for families whose child is experiencing an extended hospital stay. We started a new playgroup just for parents of children with Down syndrome ages 4 to 7. For single mothers, we began a new support group designed to meet their unique needs. All these new initiatives, along with our many other support programs, are aimed at ensuring that all families have the critical supports they need during the early years.

Our Parents First Call Program remains 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.
154 new and expectant families received personal one-on-one support, information and guidance from our First Call Program in 2017.
When John and Jeanne Doherty of Billerica heard that their daughter could be passed over if she ever needed an organ transplant, they were beside themselves. Jessica, who is 22, has Down syndrome and a medical loophole allowed medical professionals to make this determination based solely on her disability.

“She’s an important part of our family and a viable member of the community,” Jeanne said. “She should have every right that everybody else has.” Fortunately for the Dohertys and the 5,000 others with Down syndrome and their families across the state, the MDSC was equally appalled when the injustice came to our attention.

Immediately, our policy arm sprang into action, and by early 2016, we introduced a new bill, sponsored by Jim Cantwell of Marshfield, that would prohibit disability-based discrimination by doctors, hospitals and medical organizations when determining if a patient is eligible to receive an organ transplant.

As Rep. Cantwell put it at the time, “For those in line for an organ transplant, the time spent on a wait list can be anxiety-filled and life-threatening.” With no time to spare, we promptly called on our army of members to use their most powerful weapon - their real-life stories.

Jeanne heeded the call, pulling together a touching YouTube video that showed her family’s predicament and working with the MDSC to get the word out through the media - appearing in The Boston Globe and on Boston25 News.

In late May 2016, the fervor around the bill built to a crescendo at our annual Advocacy Day at the State House, which continued through the fall. By late December, we got the word: Governor Charlie Baker signed the Organ Transplant Non-Discrimination Bill into law.

As Executive Director Maureen Gallagher put it, “This is a matter of equity, fairness and compassion for those whose voices are too often silent.”
225 people attended our Buddy Walk on Washington and Down Syndrome Advocacy Day, taking action to create systemic change.
On paper, Ashley DeNoble’s journey through the Newton Public Schools may appear smooth and easy. When she was young, she sang in chorus, acted in musicals, participated in her 5th grade talent show, and has always had lot of “typical” friends. Today, she can comfortably stand on stage to read a Shakespearean sonnet, is thriving in inclusive classes at Newton South High School, and has attended both her junior and senior proms.

“ать don’t know what I wou’d have done with’out the MDSC.” But her overall success obscures the numerous critical forks-in-the-road over the years, says her mom, Allyson, including when she entered kindergarten and when she transitioned to middle school. These are the times, she notes, when the MDSC was there for their family, providing guidance, resources, and support.

“I don’t know what I would have done without the MDSC,” Allyson says. At the Educators Forum, “I have always come away with books, materials, websites, and apps that are perfect for what I need.” The Meaningful Inclusion Educator’s Manual has been a critical guide for Ashley’s teachers. And her one-on-one conversations with MDSC staff about inclusion, modifications, and other supports, have been integral to making the necessary adjustments to keep Ashley’s learning on track.

By the time Ashley graduated to middle school, Allyson had the confidence to advocate for her to quickly change to something that was a better fit. All along the way, connecting with other MDSC families has been invaluable, she says.

To give back, Allyson recently signed on to help other parents needing advice at crucial times by serving as the MDSC’s first Education Resource Parent. This new MDSC program delivers one-on-one support to MDSC families seeking education-related resources and guidance. Participants are matched with an experienced parent mentor who guides them with practical education tips and useful information.

“It’s really just so important to have a community - to have people who understand what you’re going through and can share their own experiences.”

In 2017, the MDSC continued to expand our educational resources for parents, teachers and administrators. Thousands of families in Massachusetts and beyond took advantage of education-related workshops, webpages, conferences and webinars, and we launched the Accept the Challenge Program, an educational based awareness program designed to promote understanding and acceptance of each other, regardless of differences and challenges.

For the 13th year, we hosted our Educators Forum, a professional conference for parents and educators. Over 2,600 copies of our Educator’s Guide have been distributed in four countries; planning began for our 2nd Adult Conference in spring 2018; and the MDSC has provided families and professionals with articles, resources and other tools to create effective individual educational programs for their students with Down syndrome.
1,828 General and special educators, paraprofessionals, administrators, specialists and parents learned best practices in educating students with Down syndrome through MDSC webinars, workshops, educators guide and our three major conferences - the Educators Forum, the Annual Conference, and the Adult Conference.
When Christopher Sanchez joined Advocates in Motion three years ago, he already had a circle of friends with Down syndrome. For more than a decade, Chris had been a member of Down Syndrome Folklore Latino (FLUPESD), a Spanish-language social club in the Boston area.

Both programs, his mom Patria says, have been critical cultural touchstones for Chris. She jokes that while he learned to dance merengue and salsa with FLUPESD, AIM taught him how to dance hip hop and sing karaoke.

But it didn’t take long for Chris to realize that AIM wasn’t just about making new friends. Immediately, Chris found himself learning new skills, thinking about his future in a way he never had, and having unique experiences that would facilitate his growth and maturity. Whether embarking on a kayaking trip or tackling yoga poses, Patria says, the AIM staff “never says no, you can’t do this. It’s always, yes, you can!”

As a result, Chris has become noticeably more confident. “When I bring him to the doctor now, I don’t even talk. He does all the talking,” she says. He’s also learned the whys and hows of making healthy lifestyle choices, and has internalized better habits, like cutting out sugar from his diet. “I’m happy and proud that he’s achieved as much as he has,” Patria says. “AIM has been life-changing for him.”

“Those programs are so important,” she adds. “For me, getting Chris to those programs was a struggle, but it was well worth it. He has grown in so many ways.”

In 2017, 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 13 to 22 and their families.

At AIM Hangouts, AIM Parent Meetings and AIM Socials, participants delved deeply into the theme for the year, Let’s Get Moving! Self advocates explored ways to live active, healthy, happy lives, like by making exercise fun so it doesn’t feel like a chore. Top choices included soccer, tennis, biking, and karate, but the clear winner was dancing!

At Land’s Sake Farm in Weston, participants learned about farm work and then dug right in themselves -- planting, weeding, and feeding rabbits and chickens. They wrapped up the year with a thrilling trip to SkiWard in Shrewsbury, where they bulleted downhill on a speeding tube.

“I’m happy and proud that he’s achieved as much as he has,” Patria says. “AIM has been life-changing for him.”

self advocates and peers 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 MSDC has made public awareness a top priority. In 2017, we celebrated 21 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.

Twelve years ago, when Gail and Scott Trinque got a prenatal diagnosis indicating that their first-born child, Theo, would have Down syndrome, the news was difficult to hear. But what was harder to handle was the negative reaction from medical providers and others.

“The simple answer is, when you’re passionate about something, it’s really easy to get involved and make a difference.”

That reaction from others fueled Gail and Scott Trinque’s commitment to work with the MDSC to change outdated societal perceptions about people with Down syndrome.

“We’ve approached public awareness a little differently,” Gail notes. For her, it’s about friends, family and their local community. For Scott, it’s about his company, EchoStor Technologies, a leading information technology provider, and leveraging his important connections to help others. “Anyone who knows Scott and John (Dooley, Echostor’s CEO),” Gail says, “they jump at a chance to support a cause that is near and dear to us.”

The results have been remarkable, especially in the area’s professional sports scene. Over the last four July’s, EchoStor has partnered with NESN on a so-called “HITS” campaign, in which every time a Red Sox player gets a hit, EchoStor donates $50 to the MDSC. The campaign has raised $50,000 for MDSC programs and services, and the exposure for Theo and others with Down syndrome on the field at Fenway as well as during Red Sox broadcasts has been priceless.

Scott has had a similar impact on the MDSC’s annual Bruins Alumni charity hockey game. As chair for three seasons, his involvement has been instrumental to taking the event to the next level. He helped fill roster spots by recruiting EchoStor team members and engaged his extensive business network to raise awareness – for example by scoring an interview on WAAF radio.

Gail, meanwhile, has been busy raising awareness throughout her community in Lakeville, MA, where Theo is known simply as “the Mayor.” Theo is “a bit of a celebrity in this town,” Gail says. “We can’t go anywhere without being recognized.” As a former physician’s assistant in a family practice, Gail started stepping up to counsel other families who received a pre-natal Down syndrome diagnosis. And most recently Gail has stepped into the role of Chair of the MDSC’s Parents First Call & Medical Outreach Advisory Council.

Working hand-in-hand with the MDSC, Gail and Scott have opened countless hearts and minds. The simple answer for their secret to success, Gail says, “is when you’re passionate about something, it’s really easy to get involved and make a difference.”
4,350 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.
ADVANCING MEDICAL CARE AND RESEARCH
Providing better healthcare outcomes for patients no matter where they live

Massachusetts is home to some of the best Down syndrome healthcare clinics in the world, with specialty programs at Boston Children’s Hospital, MassGeneral Hospital and UMass Medical Center. Everyday, these programs are serving MDSC members, including those with the chronic conditions that people with Down syndrome are prone to over their lifetime such as congenital heart disease, thyroid conditions, leukemia, obstructive sleep apnea, and accelerated aging.

However, even in Massachusetts, not everyone who needs it has easy access to the first-rate services and resources these clinics provide. And beyond Massachusetts, the problem reaches crisis proportions.

That’s why the MDSC has been proud to consult on a project critical to providing better healthcare outcomes for patients with Down syndrome no matter where they live. The project, which is being led by the MassGeneral Hospital Down Syndrome Program, is creating the first ever virtual Down syndrome clinic, called “Down Syndrome Clinic to You.” Funded by a $2.1 million grant from the Patient-Centered Outcomes Research Institute (PCORI), Dr. Brian Skotko, co-director of the MGH Down Syndrome Program and his team are building and testing this innovative project with help from the MDSC.

MDSC Executive Director Maureen Gallagher notes that while Down syndrome is the most common genetic condition, there are only 58 Down syndrome clinics nationwide in just 32 states and fewer than 10% of patients with Down syndrome receive information on the newest treatment recommendations when they are not connected with a specialty clinic.

“We feel this project fills an important void in the healthcare landscape for individuals with Down syndrome – that is, to have access to evidence-based recommendations to guide healthcare decisions,” Gallagher said.

Our efforts in the area of medical care and research are deep and broad. We educate healthcare professionals through Grand Rounds and Operation House Call (a collaboration with The Arc of Massachusetts). We help families and researchers make mutually beneficial connections by tasking our Medical & Scientific Advisory Council with identifying the best studies to promote. We facilitate communication between healthcare providers and scientists to promote the development of best practices for providing medical care, therapies, and Down syndrome research. And we stay on top of the latest medical and scientific developments to ensure our members have access to up-to-date, accurate information and resources pertaining to Down syndrome.

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.
Healthcare professionals received up-to-date accurate information about Down syndrome through MDSC medical outreach programs.
When Sebastian Sperling signed on as an Allen Crocker Self Advocate Intern in early 2017, he knew exactly what he would focus his service on - storytelling. By engaging young adults and adults with Down syndrome to share their experiences on film, Sebastian wanted to uncover valuable insights that could benefit him and many others.

Once on board, Sebastian went to work, setting up a series of on-camera interviews with peers, and asking straightforward questions about the issues they were dealing with in their lives - transition, employment, teamwork, etc. Launched on his own YouTube channel, the videos showed the complexity of being a person with Down syndrome - his subjects were at once unique individuals, just like anyone else their age, and facing obstacles that others often don’t.

Sebastian’s film project was a huge success. But what he didn’t know was that through the process, he would learn to share his own compelling story in the service of making a difference. In April, Sebastian joined a delegation of MDSC members to attend the Buddy Walk on Washington, where he represented the MDSC lobbying Massachusetts legislators in the nation’s capital.

“It was such a great experience,” said his mom Anne-Lise. “For Sebastian it was very inspiring to learn more about the political process and to become better at speaking to advocate.”

“Self Advocate Advisory Council & Allen Crocker Internship
Learning to tell powerful stories, including your own

Our Crocker Internship and Self Advocate Advisory Council (SAAC) give self advocates like Sebastian opportunities to drive the MDSC mission, connect and lead. The 16-member SAAC advises the MDSC Management Team on issues of importance to self advocates. The SAAC group met monthly to plan events for peers, problem-solve issues, and discuss ways to get more peers involved in the MDSC and grow our adult community.

SAAC members hosted an Open House, New Year Party, Open Mic & Game Night, and Family Bowling events. In addition, SAAC members took on leadership roles at the Annual Conference and Advocacy Day. They continued a fruitful collaboration with PricewaterhouseCoopers on financial literacy and soft skills trainings and they published the 2nd edition of a SAAC newsletter, written by self advocates for self advocates.
90 adults with Down syndrome participated in leadership activities and joined the new networking and socializing events organized by self advocates for self advocates.
YOUR NEXT STAR EMPLOYMENT INITIATIVE
Leveraging grassroots network to support integrated employment

For Jeannette Angles, who has her own 20-year-old with Down syndrome, the issue of disability employment is close to her heart.

Jeannette is one several administration officials at Babson College with personal connections to the MDSC and our Down syndrome community. “When the MDSC launched its employment initiative, I knew that Babson was a perfect fit,” said Jeannette, who previously served on the MDSC Board of Directors. “There were just so many points of contact.”

With 30-plus years of grassroots advocacy experience, MDSC is fortunate to have deep connections throughout the communities we serve. And these connections have proved invaluable at places like Babson, which has both individual leaders committed to hiring a diverse workforce and a culture of acceptance and inclusion.

Jeannette has formed an especially close connection with Sanaz Safarizadeh, who Babson hired last summer through MDSC’s Your Next Star initiative to work in the Public Safety Department. Jeannette has become a friend and personal mentor, crossing campus to check in on Sanaz and discussing future plans with her. Jeannette has even started talking to Sanaz’s family to share resources and provide support.

Jeannette said she was inspired to be involved in the campaign when she was serving on the board and watching Your Next Star being developed and launched. “I am really just a cheerleader, but I know that if a placement is going to be successful, there has to be natural supports,” she said. “I’m grateful I can be one of those natural supports.”

In October 2015, the MDSC launched Your Next Star, our web-based disability employment portal designed to open the eyes of employers to the benefits of hiring people with Down syndrome and other intellectual disabilities.

Located at www.yournextstar.com, Your Next Star enables users to take action by contacting their elected officials, helping a friend get a job, or sharing their own story. It also offers employers streamlined, step-by-step guidance on how to hire someone.

Since its launch, Your Next Star has significantly expanded opportunities for people with intellectual disabilities in Massachusetts. As of 2017, we had actively engaged over 200 employers, reached more than 1,600 people through campaign presentations, and formed critical partnerships with employers, including institutions of higher learning and law firms.

YNS videos and website have been viewed more than 20,000 times in the past two years, and the campaign has been featured as a centerpiece at the Work Without Limits’ Annual Conference and MDSC’s Annual Educators Forum, as well as in The Boston Globe and on Boston25 News.
1,650 employers, human resource professionals, partners and others reached through in-person presentations of the Your Next Star employment campaign
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Jacquie Sherman
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