Extraordinary Stories, Inspiring Endless Possibility Throughout MA and Beyond
In 2018, with your support, MDSC made a significant impact in the lives of people with Down syndrome and their families across the Commonwealth.

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.

Parents First Call, the bedrock program for the MDSC, provided new and expectant families with 24/7 support from our team of trained parent mentors. First Call continues to grow in size and scope. We now have more than 60 volunteers across the state who are available to listen, share their journeys, answer questions, and provide valuable information.

We have more support offerings than ever before to meet the particular needs of each of our members.

We have a new 4-7 Playgroup, just for parents of children with Down syndrome from 4 to 7 years old. Our MDSC Cares Program provides a care package for families whose child with Down syndrome is experiencing an extended hospital stay or ongoing complex medical care. We offer a wide range of personalized supports that meet families “where they’re at”: a Single Mom’s Group; a ‘Family with Twins Social’, baby massage and sign language classes; support groups for Spanish-speaking families and families of diverse backgrounds; New Family Socials; and Grandparents Get-Togethers. We give special attention to our families with loved ones with special health care needs, including hosting a Complex Needs Support Group.

As children grow, our educational initiatives become critically important. We understand the challenges inherent in navigating the educational maze. We are adept at connecting schools with valuable resources and keeping up with the latest best practices in order to ensure that our loved ones get the best, most inclusive education possible.

Last year, we were thrilled to pilot our Resource Parent Volunteer Program to provide personal support to MDSC families seeking resources and guidance related to education, including fact sheets and webinar materials. Through the program, parents of children with Down syndrome are trained on best practices in education and peer-to-peer support.

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. Available online and at MDSC events, the manual has sold over 2,600 copies since last year and has become an essential guide for special education teachers and parents here in Massachusetts and beyond.

As part of our Strategic Plan, we are committed to serving individuals with Down syndrome for their entire lives, including during the teen years and throughout adulthood. Our Self Advocate Programs will continue to be a critical part of our programming in 2019.

Our 2nd Adult Conference was a huge success, bringing together experts from around the country to engage in topics specifically geared to adults with Down syndrome and their families.
In 2019, our Self Advocate Advisory Council (SAAC), which gives self advocates with Down syndrome 22 and older opportunities to lead, network and socialize, will continue to represent the larger self advocate community while advising MDSC on issues important to all individuals with Down syndrome throughout the Commonwealth.

Our signature Advocates in Motion (AIM) Program for teens and young adults ages 13 to 22 develops leadership and self-advocacy skills and builds self-confidence in an encouraging environment.

MDSC has made statewide advocacy a hallmark over the last 7 years, helping move legislation that is changing lives - the Down Syndrome Information Act, Real Lives Bill, National Background Check Bill, and the most recently passed Organ Transplant Bill are making necessary changes to improve lives.

The primary vehicle for advancing our policy priorities, our Annual Down Syndrome Advocacy Day, will be held again this spring. The 6th Annual event will take place at the Massachusetts State House, where our community will connect with legislators, and share our personal stories and challenges. We look forward to hundreds of our members gathering at the Grand Staircase for a lunchtime reception and speeches before fanning out throughout the building to meet with legislators.

MDSC’s Board of Directors last year once again made raising public awareness about our community as our organization’s top priority. Through our Buddy Walk Program and Your Next Star Employment Campaign, we raise awareness at events throughout the state, online and in traditional news outlets.

In 2018, our Buddy Walk Program, featuring three walks around the state - Buddy Walk by the Sea in Hyannis, Buddy Walk & Harvest Fair in Westborough and Buddy Walk & Family Festival in Wakefield - raised more $550,000 to support our programs. And throughout the year, we shared Extraordinary Stories with our community.

2018 was a banner year for our Your Next Star Employment Initiative, which outreaches to employers to help them understand the value that people with Down syndrome bring to the workplace. With stories on Boston25 News, in the Boston Globe, and an appearance at the United Nations on World Down Syndrome Day, Your Next Star has also entered the public sphere.

In 2019, our Management Team begins the final two years of our Board of Directors-approved 5-year Strategic Plan, an ambitious blueprint for expanding our resources, programs and advocacy for the future.

At the center of our 2016-2020 Strategic Plan is designing a program-and-services model that serves individuals and families across the lifespan; builds a community that fosters and sustains a sense of belonging; and increases capacity to ensure that MDSC has a sustainable financial foundation for the future.

So many of you, in your own individual way, have helped MDSC achieve our mission in 2018. 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 2019 with more opportunities for our community than ever before. Thank you for all you have done to make 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
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 about the possibilities and potential of all people with Down syndrome throughout their lifetime.
- To provide a clearinghouse of information and resources related to Down syndrome and other intellectual and developmental disabilities 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 advocate for improved systemic change and policy in issues such as community inclusion and employment for adults with Down syndrome.
- To empower all people with Down syndrome to become effective self-advocates.
- To advocate for all individuals with Down syndrome to have access to high quality medical services and research.
- To ensure that expectant and new families receive accurate and up-to-date information and desired supports.

Cover Photo by Mark Hunt of DisabilityImages.com
As a community and as individuals, we are natural storytellers. This is, in part, because people with Down syndrome across the world are accomplishing incredible feats - climbing the world's tallest mountains, performing on the world’s biggest stages, and starting their own remarkably successful businesses in a range of fields from retail to public speaking.

On a local level, too, our loved ones with Down syndrome have equally remarkable stories to share about how they are learning in classrooms alongside their peers, participating in extracurriculars with their friends, working in their local businesses, advocating for themselves with their lawmakers, and generally, pursuing life to its fullest.

Our stories resonate deeply, in part, because outside our community, the public often has little to no knowledge about what people with Down syndrome are capable of. Our families, friends, neighbors, school teachers, co-workers, doctors, etc. often don’t know who we are, how far we’ve come and how far we still have to go.

In 2018, we were thrilled to work with our members to explore our individual and collective Extraordinary Stories. We were proud to spread the word about our accomplishments, change the countless misperceptions, educate others about our challenges, and ultimately, help the world understand the uniqueness of each and every individual with Down syndrome.

That’s why we chose as our theme for 2018, Extraordinary Stories. Our loved ones with Down syndrome, each of whom has an extra copy of chromosome 21, not only have stories to tell, they have Extraordinary Stories.

Our stories are truly extraordinary, and we loved sharing our community’s Extraordinary Stories with the world.
2018 FINANCIAL STATEMENT
Connecting Revenue with Expenses
For Fiscal Year Ending June 30, 2018

REVENUE
Total Revenue $1,927,399

EXPENSES
Total Expenses: $1,672,952

For more detailed financial information, please contact us at mdsc@mdsc.org.
PARENTS FIRST CALL
Guiding families on their journey

When Kerry and Tom Neenan found out in the second trimester that their first child would be born with a heart condition and Down syndrome, they launched into action. First, they underwent a series of medical tests to gather more information about their daughter’s heart.

Second, they reached out to MDSC to learn everything they could about Down syndrome. Immediately they were connected with a First Call parent volunteer, who they are still close with today. Then, about a week before Maeve was born, Kerry and Tom attended a Prenatal Social at the MDSC office.

“That contact with real families was the most beneficial thing to us in our journey to accepting our daughter’s diagnosis before she was born,” they say. “I remember leaving feeling that there was going to be this community of support that was going to be there for us,” Tom says.

The Neenans recall the first three months of Maeve’s life as a blur leading up to her heart surgery, but they did manage to attend their first New Family Social. “We didn’t know many people there and it was a bit overwhelming at first,” they say. “But it was so great seeing other kids with Down syndrome and parents who knew exactly what we were going through. It was instantly like a big family.”

It didn’t take long for Kerry and Tom to start giving back. Not only did they create their Maeve’s Marauders Buddy Walk team, Kerry joined the Buddy Walk Committee to help plan the event, trained to be a First Call Parent volunteer to support other families, and joined the Parents First Call Advisory Council.

Even while giving back, the Neenans still make a point to attend every quarterly New Family Social. “I really have no idea what Tom and I would do without the MDSC. They’ve become such an integral part of our lives.”
new and expectant families received personal one-on-one support, information and guidance from our First Call Program in 2018
Back in 2005, Kate Bartlett of Arlington got a call from Senator Kennedy’s office. They wanted her, along with other individuals with disabilities, to come testify at a Senate hearing about their experience working in a competitive employment environment rather than a sheltered workshop. “I was nervous, but I just talked about how I’m living a normal life,” says Kate, who was in college at the time.

Fourteen years later, Kate – like hundreds of other MDSC members – has taken advantage of opportunities through MDSC to hone her advocacy skills. She became a member of the MDSC Self-Advocate Advisory Council and, in 2014, she joined MDSC’s delegation to attend her first NDSS Buddy Walk on Washington. Now, she has gone back every year since to help lobby for MDSC’s national priorities on Capitol Hill. And, in recent years, she’s testified multiple times at the State House – for bills related to higher education opportunities and housing creation.

Like so many MDSC members, Kate is motivated by her desire to ensure that all people with Down syndrome are afforded every opportunity in life. “I think everybody should be able to go to college and earn a degree,” and live independently, she says. With MDSC behind her, Kate has become a pro at using her voice to speak on behalf of her peers, helping to improve the lives of all people with Down syndrome and other disabilities.

Over the years, MDSC’s advocacy efforts have meaningfully improved the lives of countless individuals with Down syndrome by the passage of key legislation. As Kate is the first to say, the opportunities she’s had to participate in MDSC’s advocacy efforts have also profoundly benefited and empowered her.

Her advocacy work has been a catalyst for her to take some bold steps, she says. “I think what makes me independent is I can travel without my parents,” says Kate, recalling how she was invited by MDSC to attend a congressional hearing on Down syndrome and Alzheimer’s in 2017.

Today, Kate’s mom, Jan, sees the difference. “She is much more comfortable and confident talking to legislators. But not just legislators, talking to anybody.”

MDSC has made statewide advocacy a hallmark over the last 7 years, establishing itself as a leader in disability policy by helping move legislation that is changing lives. The list of successes is long – Organ Transplant Bill in 2016, Real Lives Bill in 2015, National Criminal Background Check Bill in 2014 and the Down Syndrome Information Act in 2012. On the national level, MDSC helped pass the Achieving a Better Life Experience (ABLE) Act, a landmark bill that gives people with disabilities the ability to create tax-free savings accounts.

In May 2018, we held our 5th Annual Advocacy Day at the State House, where we honored Governor Charlie Baker with our Legislative Champion of the Year Award. The event has become a launching pad for the eventual passage of our key policy initiatives, and we continue to push for our priority Higher Education Bill, which will remove barriers that preclude people with intellectual disabilities from attending college.
250 people attended the Buddy Walk on Washington and Down Syndrome Advocacy Day, taking action to create systemic change.
Bella Padula is only in the 4th grade, but already her journey through her local public schools has been eventful.

“Overall, our school has been really supportive,” says Bella’s mom, Jessica, “but there’s been bumps along the way. Every year brings different challenges, and it’s been great to have the MDSC there.” A long time MDSC member, Jessica says she’s been fortunate to have a community of other MDSCers to confer with.

“Every year brings different challenges, and it’s been great to have the MDSC there.”

Jessica, who runs Speech & Language Specialties, Inc., is a speech-language pathologist with a deep understanding of the best practices for educating children with disabilities. She is a strong advocate for her daughter Bella as well as for the many other children she works with.

The MDSC Educators Forum has become an important resource for Jessica’s school system and family. She has successfully advocated for Bella’s school to send as many educators as possible to attend so they can learn the latest best practices from regional and national disability education experts. Last year, Bella’s school sent a speech pathologist, occupational therapist, board-certified behavior analyst, instructional assistant, two special education teachers and a classroom teacher.

“It’s been a great platform for Bella’s teachers to go and learn about different resources they can use to modify the curriculum and truly understand an inclusion model.”

In 2018, MDSC piloted a Resource Parent Volunteer Program to provide personal support to MDSC families seeking resources and guidance related to education, including fact sheets and webinar materials. Through the program, parents of children with Down syndrome are trained on best practices in education and peer-to-peer support. In addition, thousands of families took advantage of education-related workshops, webpages, conferences and webinars. For the 13th year, we hosted our Educators Forum, a professional conference for parents and educators and over 2,600 copies of our Educator’s Guide have been distributed nationwide and overseas.
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.
For CJ Buckley of North Attleboro, turning 13 was literally a life-changing experience. As a teenager, he was finally eligible to join the MDSC’s Advocates in Motion program. “We’d been involved in MDSC since he was born,” says his mom Sandra, “so we’d been waiting for it.”

As an August birthday, she noted, the timing was perfect for CJ to jump right into the new AIM year the month after he turned 13.

With robust programming for parents and kids alike, AIM immediately got the entire family thinking about the future. “Since we lived far away, I always stayed for the parent sessions,” Sandra says. “Even if it was transition information that wasn’t relevant for us yet, I just put it in my back pocket. I didn’t want to miss it.”

As for CJ, AIM has him dreaming big. After a session about staying active or career exploration, he inevitably comes out with big dreams, Sandra says. “He always comes out with life plans. He’s not going to work at some small place. He’s going to work for Google or be a professional athlete. It’s always whatever times 100.”

Being in AIM, she says, “has helped him talk about what he wants, his goals in life and not be afraid to voice his thoughts.” Plus, the socializing CJ gets at AIM is refreshingly different than other parts of his life. “At school, with his typical friends, he tends to want to entertain them,” she says. “It helps him to be around kids his age with Down syndrome. In some ways, I think he has truer bonds with them.”

In 2018, 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. During AIM Hangouts and Socials, the youth participants delved deeply into their “Together we Can” theme, giving them opportunities to get out into the community, work as a team, and learn about how to make the world a better place. 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.
self advocates between 13 and 22 gained leadership skills, life skills, and made friends in our Advocates in Motion Program
PUBLIC AWARENESS
Helping families teach their communities about life with Down syndrome

It is fitting that MDSC’s Buddy Walk was one of the first things Melissa Elow learned about Down syndrome when her son Micaiah was born in 2009. “A nurse at the hospital told me about it,” Melissa recalls. It’s since become a major part of her family’s life.

“The Buddy Walk is what opened up the Down syndrome community to us.”

At the time, Melissa knew just one person with Down syndrome, her cousin’s sister’s niece. That soon changed. Before Micaiah was 2, the Elows – including husband Darryl, sister Imani, brother Kendall – attended their first Buddy Walk in Wakefield, and they’ve been going ever since. “Everyone looks forward to it. It’s what opened up the Down syndrome community to us.”

The event itself, she says, is a true celebration. “My family, my husband’s family, people from church, friends. They all come, and every year, someone new says to me, can I walk with you?”

But as much as the event is about having fun, the Elows recognize that raising awareness is equally important. “It was a learning experience for all of us. Seeing all the children and adults with Down syndrome and what they’re capable of, it gives them a new perspective.”

Over the years, Melissa and Darryl have mastered the art of leveraging the Buddy Walk to raise awareness. At the Curley School in Jamaica Plain, the Morning Star Baptist Church in Mattapan, and on social media, the Elows recruit team members and make sure people can get to know Micaiah’s charming personality.

They dubbed their team “Micaiah’s Army” and for the big day itself, they make their own custom camouflage Buddy Walk t-shirts with Micaiah’s image. That way, even after the event, the 40+ members of their team can wear their Micaiah’s Army swag, raising awareness wherever they go.
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
Promoting critical studies that will improve lives for the longterm

Over the past 15-plus years, studies have repeatedly shown the effectiveness of a breakthrough behavioral intervention that uses developmental skills to improve behaviors, emotional responses, social communication skills and overall development in children with disabilities.

A behavioral therapy called JASPER (Joint Attention, Symbolic Play, Engagement, Regulation), which was developed at UCLA, has been tested and proven effective in randomized trials involving nearly 500 children with autism. Now, researchers at Boston Children’s Hospital’s (BCH) Down Syndrome Program and Laboratories of Cognitive Neuroscience are conducting a trial of the intervention on 3-year-olds with Down syndrome.

They are hopeful that like with individuals with autism, children with Down syndrome will show improvements in joint engagement, social communication, and emotion regulation, as well as parental co-regulation strategies.

So with such an important mission on the line, and BCH looking for a partner to get the word out, who did they call? MDSC of course.

MDSC takes its charge to promote select studies seriously, which is why we’ve developed an expert Medical & Scientific Advisory Council (MSAC). Like all studies, the MSAC put JASPER through a rigorous approval process that stringently reviews content, ethical standards, and feasibility, while ensuring privacy for our families.

Once approved, MDSC partners with researchers to develop a study dissemination plan that complements their other recruitment strategies. “A lot of studies normally have to generate three times as many contacts as they actually need,” Hojlo says, in order to meet target numbers. “Especially something like this that families are not used to because it’s a first-of-its-kind.”

That’s why, Hojlo says, MDSC’s support – with our reputation as a trusted brand with the ability to reach deeply and broadly into the Down syndrome community – has been essential for recruiting participants and making the study successful.

“With such an important mission on the line, and BCH looking for a partner to get the word out, who did they call? MDSC”

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
Elizabeth Zamudio came into MDSC’s Self Advocate Advisory Council (SAAC) looking for a social peer group that she could relate to. “She tends to be more reserved in new environments and around new people,” Elizabeth’s father Francisco points out. In addition, as a bilingual Spanish/English speaker, he says, “our kids have more challenges, because on top of speaking two languages, they are immersed in two different cultures.”

But the SAAC is not your average social group. With inclusion, empowerment, self-determination, and recognizing the strengths that each individual brings to the table as core principles, it didn’t take long for Elizabeth to thrive. “With each passing year, it is evident that she has become more confident in herself and her ability to raise her voice.”

In fact, not only has Elizabeth become more friendly and open to others, Francisco says, SAAC has become “a lifestyle” for her. “She knows the players, and is thrilled to encounter them again and again,” he says. “She sees no barriers, no walls, no boundaries. She is just there to learn, have fun, socialize and participate in the community.”

“Elizabeth’s confidence and pride are all worth it,” he adds.
adults with Down syndrome participated in leadership activities and joined networking and socializing events organized by self advocates for self advocates.
Like any dedicated employee who works a job for a long time, John Dunleavy keeps accumulating responsibilities – delivering mail, maintaining photocopiers, filling orders, handling Bruins and Celtics ticketing, and replenishing the break room.

Officially, John works in the operations division of the TD Garden, where he has his own badge and desk and attends meetings. After 9 years as a beloved team member, he has also become a sort of unofficial ambassador. He routinely gets invited to the VIP area to socialize when he attends games. “Everybody knows him,” says his mom Toni.

Though remarkable, John’s story is not unique, which is why we created the Your Next Star employment campaign, to make sure that other employers understood the true value that people with Down syndrome bring to their workplace.

“Now, John’s resume is bursting not only with job responsibilities, but extracurriculars too.”

John’s involvement with MDSC and Your Next Star has also served as a launching pad for him, starting with when he was keynote speaker at the 2014 Annual Conference. “That gave him a lot of confidence,” Toni says, “when he stood up in front of 600 people. After that, he became more involved in public speaking.”

When the Boston Bruins celebrated “Hockey is for Everyone” Night in February 2018, they interviewed John live in the control room, broadcasting it on the jumbotron during intermission.

Now, John’s resume is bursting not only with job responsibilities, but extracurriculars too – MDSC Self Advocate Advisory Council member, honorary coach for Bruins Alumni team, Winchester High School Sports Hall of Fame inductee, etc. In 2018, John found himself back onstage at MDSC’s Annual Conference, this time to present his boss, Boston Bruins Foundation Executive Director Bob Sweeney, with MDSC’s Employer of the Year Award.
employers, human resource professionals, partners and others reached through presentations of the Your Next Star employment campaign

17,950
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