



2015 ANNUAL REPORT

**LEADING
THE WAY IN
MASSACHUSETTS
TO MAKE A WORLD
OF DIFFERENCE**

MESSAGE FROM OUR LEADERSHIP

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 2015.

"So many of you, in your own individual way, have helped the MDSC achieve our mission in 2015"

We launched our new public awareness campaign, *Your Next Star*, aimed at opening the eyes of employers to the power of people with Down syndrome in the workplace. Two years in the making, *Your Next Star* came about because of our increasing awareness of the challenges facing adults with Down syndrome looking for meaningful work opportunities in their communities.

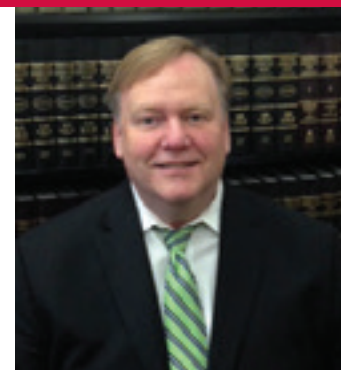
For more than 30 years, MDSC has worked tirelessly to provide information, networking opportunities, and advocacy for individuals with Down syndrome and their families.

In 2013, we conducted a comprehensive Membership Survey, the first such undertaking in our history. The 450 responses proved to be a wealth of data perfect for guiding our planning and activities for the future.

Among the critical needs the survey identified was a shortage of growth opportunities for our self-advocate members after leaving high school. It was reported in stark terms that our adult self advocates and their families were frustrated by unsuccessful attempts to find good work in their communities.



Maureen Gallagher



Steve Narey

Upon further investigation, we found that people with Down syndrome and other disabilities have drastically higher unemployment rates than their non-disabled peers despite typically showing more loyalty and lower turnover, and having similar job performance ratings.

The *Your Next Star* public awareness campaign is the MDSC's attempt to change that.

For the MDSC and our members, people with Down syndrome having successful work lives directly relates to everything we do. Expectant parents need to know their children will have complete, fulfilling lives as adults. Families with school-age children need to know all their educational efforts will pay off in the "real world." And employment is a huge part of the equation when talking about all our programs, whether it's related to inclusion, leadership or social opportunities.

With the launch of *Your Next Star*, the MDSC is charting a course into new territory. Speaking of new territory, the MDSC held its first ever adult conference in 2015. *Growing up with Down Syndrome: Living a Longer, Healthier and*

Meaningful Life, was organized in collaboration with the Massachusetts General Hospital Down Syndrome Program specifically for adults with Down syndrome ages 21 and up and their families. This conference represents a major step in the MDSC's commitment to strategically address the needs of all our families throughout the lifespan. Key issues such as adult health care, living and working in the community, and aging concerns were all addressed at this conference.

The MDSC is tackling some of the most significant challenges facing our loved ones with Down syndrome. Our new 2016-2020 strategic plan that our Board of Directors approved this past June, calls for positioning the MDSC as the pivotal organizational resource in supporting, in an active lifetime partnership, individuals with Down syndrome, their families and support network.

By working together, we can ensure that all people with Down syndrome and other intellectual and developmental disabilities are engaged in meaningful opportunities in their communities.

Throughout this report you can see how the MDSC is making a world of difference from supporting families through our Parents First Call program; providing educational initiatives for families of school aged children;

empowering self-advocates through our Advocates in Motion program and Self Advocate Advisory Council; and leading the way with our critical public awareness and advocacy efforts.

We also have two affiliate programs: Dads Appreciating Down Syndrome (DADS) and the Down Syndrome Autism Connection (DSAC) that host a variety of activities for families.

So many of you, in your own individual way, have helped the MDSC achieve our mission in 2015. 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 2016 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 are truly valued and appreciated.



Maureen Gallagher, MS
Executive Director
Massachusetts Down Syndrome Congress



Steve Narey, Esq
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.

Cover Photo by Kat Newland Photography

OUR PURPOSES

- To better educate the public in Massachusetts about the possibilities and potential of all people with Down syndrome.
- 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 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.
- To identify, develop and disseminate best practices for supporting all individuals with Down syndrome and their families throughout their lives.





LEADING THE WAY IN MASSACHUSETTS TO MAKE A WORLD OF DIFFERENCE

Every year, about 100 babies in Massachusetts are born with Down syndrome. In some sense, our job at the MDSC is easy. It's spelled out in our mission statement: ensure that each baby, each child, each teen, each adult with Down syndrome in Massachusetts is valued, included, and given opportunities to pursue fulfilling lives.

But, society being as it is, having the chance to pursue a fulfilling life for people with Down syndrome is far from easy. It's actually a very complex undertaking that requires the utmost commitment, coordination and tenacity.

In 2015 we chose the theme, "The World is Ours."

"The World is Ours" signifies that people with Down syndrome are taking more ownership over all aspects of their lives - education, employment, health care, public policy and recreation. In 2015, our members are increasingly empowered in the worlds they encompass - whether in our own communities or in the larger society. The world is *"ours!"*

"The World Is Ours" also relates to the broad reach of the

MDSC. More than ever, we are national leaders in virtually everything we do: Parents First Call, Advocates in Motion, Self Advocate Advisory Council, Public Policy, Public Awareness, Education and Medical Care & Research.

In many respects, the MDSC in 2015 is even a global organization – replicating our First Call program around the country, advising other organizations on how to advocate for crucial policies that will improve lives, providing supports for Spanish-language families and others of diverse backgrounds, connecting with new immigrants from countries like Iran and Nigeria, getting media mentions as far away as Japan, and interacting with people from all over the world who are visiting our website, watching our webinars and joining our social networks.

The world truly is ours and with your support, we're getting closer each and every day to making our dream become a reality – ensuring that our loved ones with Down syndrome can live a meaningful life while participating in all aspects of their communities.

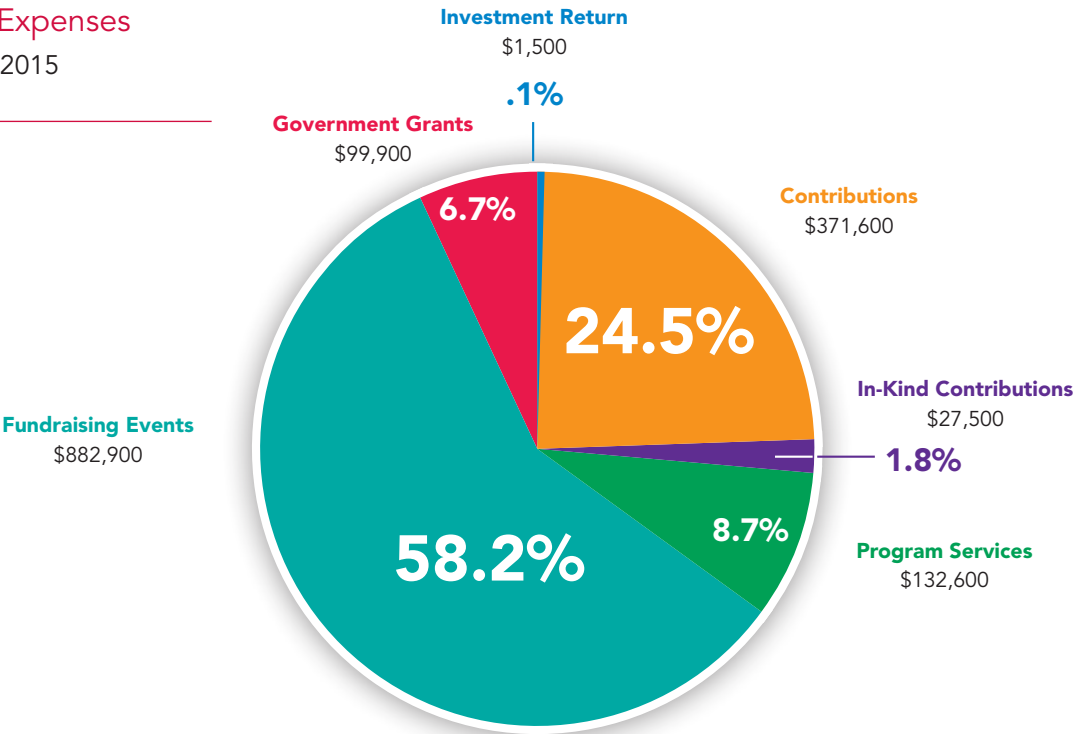
2015 FINANCIAL STATEMENT

Connecting Revenue with Expenses

For Fiscal Year Ending June 30, 2015

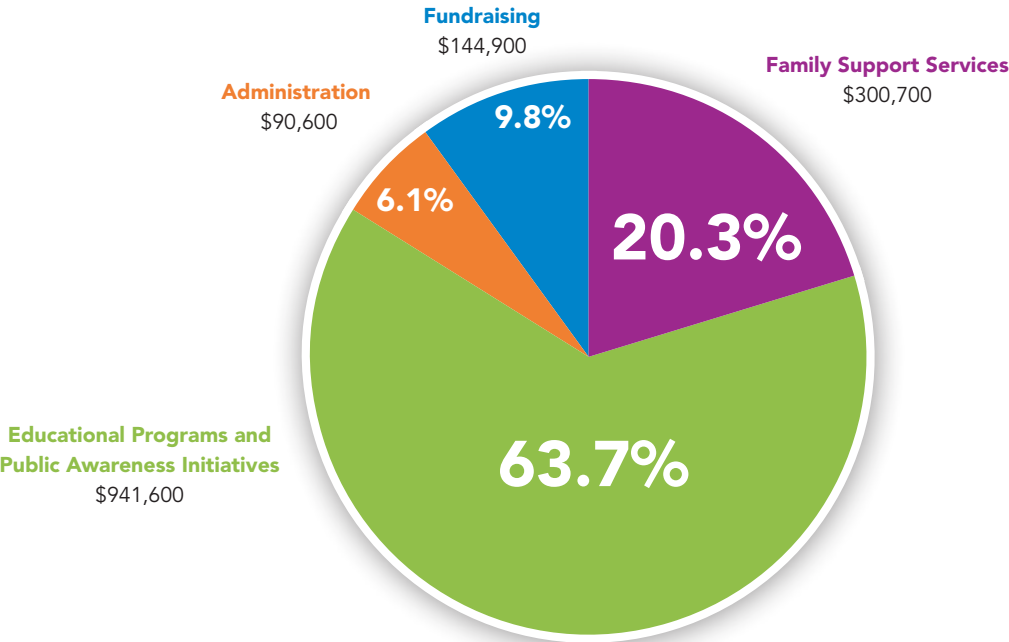
REVENUE

Total Revenue \$1,516,000



EXPENSES

Total Expenses: \$1,477,800





SELF ADVOCATE ADVISORY COUNCIL & ALLEN CROCKER INTERNSHIP

Building Confidence, Leadership, Friendship

Ned Reichenbach is the quintessential Self Advocate Advisory Council member – he works hard and (oftentimes as a reward for his efforts) plays hard.

"I'm learning to work with other people and plan activities, and I love being part of something bigger."

- Ned Reichenbach

As the Council's newest member, Ned is on a steep learning curve, a little nervous at first, but quickly hitting his stride, "jumping in with thoughtful suggestions and ideas for how to better serve adults throughout the state," says program director Colleen Endres.

Having previously served as an MDSC Allen Crocker Self Advocate Intern, Ned came to the Council with a wealth of experience. But being a SAAC member is something new and transformative,

Ned says. "I'm learning to work with other people and plan activities," he says, "and I love being part of something bigger."

Ned, along with his 13 colleagues on the Council, is helping organize and host a New Year's Bash, Spring Fashion Show, and quarterly get-togethers. They are pulling together a Buddy Walk & Family Festival team, and preparing workshops and presentations for the Annual Conference Self Advocate track.

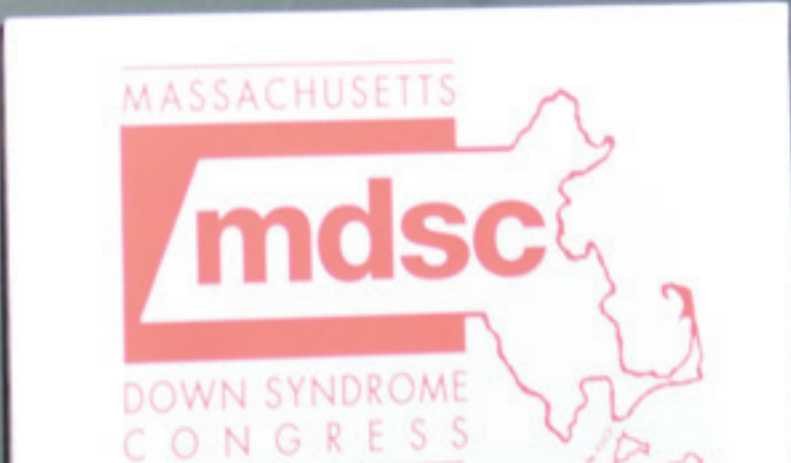
As the Council's newest member, Ned is



adults with Down syndrome
joined the new networking
leadership and socializing
events organized by self
advocates for self advocates.

The SAAC and the Allen C. Crocker Internship programs are giving self advocates like Ned opportunities to drive the MDSC mission, connect and lead. They are not only advising the MDSC Management Team on issues of importance to self advocates, they are also taking on more members to support and empower, and tackling what would have once seemed like an impossibly complex undertaking – developing a social network for adults to end the isolation that so many of our loved ones with Down syndrome experience after they transition to adulthood. By organizing regular adult socials, complete with dining, dancing and fashion shows, SAAC leaders are working incredibly hard to create a better life for themselves and others.





PUBLIC POLICY

Systemic Change with Real-World Impact

For Shey Jaboin and Tara Toussaint, advocacy has become a way of life since the family emigrated from Haiti 35 years ago. Disability rights is a civil rights issue and “the MDSC is helping give me and Tara a voice,” Shey says.

The mother-daughter duo relishes every opportunity to walk the halls of the State House and Congress. Taking advantage of MDSC advocacy initiatives, Shey and Tara have joined the Massachusetts delegation at the Buddy Walk on Washington, lobbied for critical disability policies and funding at our annual Advocacy Day, and taken an active role on our Government Affairs Committee.

In the process, Shey and Tara have made real connections with their state and federal legislators, not to mention other disability champions and power-brokers. “They now understand where I’m coming from.”

As a partner with the MDSC, their efforts paid major dividends in 2015, with the passage of three landmark bills – National Background Check and Real Lives on the state level and the ABLE Act on the federal level – which together will make a difference in Tara’s life and in the lives of millions of others for decades to come.

“We have to be sure our representatives understand that just because someone doesn’t speak verbally doesn’t mean her rights aren’t just as important,” Shey says.

*Disability rights
is a civil rights
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MDSC is helping
give me and
Tara a voice.”*

- Shey Jaboin



people attended our Buddy Walk on
Washington and Down Syndrome
Advocacy Day, taking action to
create systemic change.

In 2015, the MDSC solidified its position as a disability policy leader in the state and the country. We led the charge to revamp, push and ultimately pass a National Background Check Bill that will protect our members and the broader disability population for decades to come. We worked with our disability partners around the state to pass the Real Lives Bill, which shifts the power of choosing services back to consumers. And, after having stood apart as the first, and perhaps only, state in the country whose entire Congressional delegation signed on to the ABLE Act, we helped pass that federal legislation, finally giving people with disabilities the ability to create tax-free savings accounts.





EDUCATION

Giving Educators the Tools – and Parents the Confidence – They Need

When their twin daughter Anna was diagnosed at birth with Down syndrome, Maria Minguell and Israel Ruiz got right to work educating themselves about the possibilities.

Within two months, they found themselves at the MDSC's 2007 Annual Conference, soaking up information and making connections to help Anna reach her full potential. "The annual conference is awesome because it gives you a sense of what's next," Maria said.

*"I know no
matter how big
a problem we
have, we are not
the first to go
through it, and
the MDSC will
be there for us."*

- Maria Minguell

What came next for the Ruizes was the realization that the MDSC must play a central role in Anna's education. And so they started bringing Anna's educators into the MDSC orbit – ensuring their attendance at both the Annual Conference and Educators Forum. ("They always come back inspired," Maria says.)

Maria connected directly with MDSC Education Director Mo Blazejewski. Mo has been immensely helpful, according to Maria, and made sure that Anna's teachers had copies of

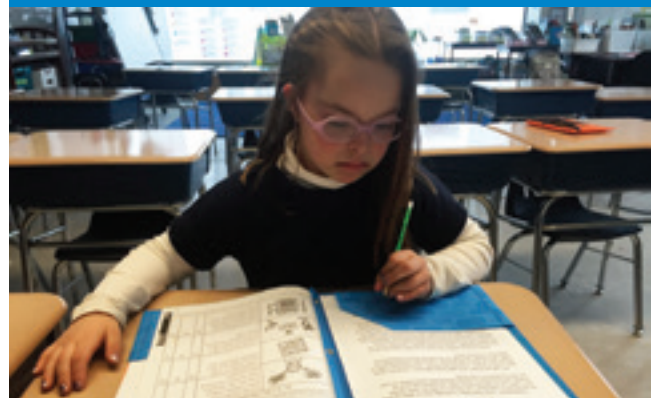
Meaningful Inclusion for Students with Down Syndrome, the new MDSC elementary education resource guide, at their fingertips.

Like the MDSC, Maria and Israel understand that teaching students with Down syndrome is not a trial-and-error enterprise. "I'm not expecting teachers to know everything about Anna her first day, but they don't have six months either," Maria says.

The Ruizes also understand that Anna – now in third grade at Boston's Eliot K-8 Innovation School – has a long road ahead, and they feel confident having the MDSC in their corner. "I know no matter how big a problem we have," Maria says, "we are not the first to go through it, and the MDSC will be there for us."

The MDSC expanded its educational resources for parents, teachers and administrators in 2015. Thousands of families in Massachusetts and beyond took advantage of education-related workshops, webpages, conferences and webinars. The MDSC also provided families and professionals with articles, resources and other tools to create effective individual educational programs for their students with Down syndrome.

Published in 2014, the MDSC's education manual, *"Meaningful Inclusion for Students with Down Syndrome: An Educator's Guide,"* has quickly become a national model, with more than 1,100 manuals having been distributed to 40 U.S. states and Canadian provinces.



general and special educators, paraprofessionals, administrators, specialists and parents learned best practices in educating students with Down syndrome through MDSC webinars, workshops and our two major conferences, the Educators Forum and the Annual Conference.



ADVOCATES IN MOTION

Empowering Self Advocates Through Friendship

One day last spring, Jordan Caira came home from her Advocates in Motion session on career planning saying something she'd never said before – she wanted a job.

Her parents were surprised, but they shouldn't have been, said Jordan's mom, Cheryl. Jordan, who has an incredible, close-knit group of friends from Framingham High School, had been hearing them talk for months, if not more, about their dreams for the future.

"AIM gave Jordan the tools and information to engage new aspects of herself and the confidence to start doing something about it."

- Cheryl Caira

Just like it has for many others over the years, AIM gave Jordan the tools and information to engage new aspects of herself, and the confidence to start doing something about it.

When Jordan first joined AIM at 14, "it came at just the right time because it really filled a void," her mom said. Jordan had always been a part of her local community in very inclusive ways, but being a part of AIM presented a different challenge and offered a new kind of growth.

And grow she has, both within AIM and well beyond. She recently offered the keynote address at our Educator's Forum and went on television with her friends to talk about their high school inclusion campaign. Now, at 19, she is working as an usher at the local AMC cinema and going to school away from home at the Berkshire Hills Music Academy.

AIM really helped Jordan become the person she is today, her mom said, someone who is comfortable in her own skin and out in the world.

In 2015, the MDSC's A.I.M. Teen & Young Adult Program provided fun, challenging, educational programming for more than 200 teens and young adults from 13 to 22, with and without Down syndrome. Participants develop leadership and self-advocacy skills, form meaningful relationships, and build self-confidence, not to mention having fun with dance, yoga and sports, and at events like their annual Halloween and holiday parties.

Their theme for the year was "Going on an Adventure!" and they did so by exploring their own personal preferences and pushing their boundaries. Events included indoor kayaking, Boston Ballet's The Nutcracker, and learning about holiday traditions around the world.



self advocates between 13 and 22 and other program participants gained leadership skills, life skills, and friendships in our Advocates in Motion Program.



PARENTS FIRST CALL

Energizing New Families About the Journey Ahead

By the time Mia June Campbell was born on July 2, 2014, her parents Leah and Matt had already been through the emotional roller coaster of a lifetime.

"We hung up the phone [with the MDSC] knowing we had an ally and someone we could count always on in the future"

- Leah Campbell

It was scarcely nine months earlier they got the thrilling – though unexpected – news that Leah was pregnant. Not long after, they got news that was even more surprising – their child would have Down syndrome. "I immediately drove home from work trying so hard to hold it together," Leah said, "but in a matter of minutes was sobbing alone in my car."

The Campbells weren't alone for long – they quickly connected with the MDSC's Parents First Call Program and its director Sarah Cullen. "There are no words to describe the value of that phone call," Leah said. "She listened, answered questions, shared her own experiences, and made us feel so supported."

The call was followed by books and onesies from the MDSC, but most importantly, Leah said, First Call had "energized us about our journey." By the time Leah gave birth to their beautiful daughter, the new parents' emotional turmoil was firmly in the past, and "we had both never been more in love in our entire lives."

Ever since, the Campbells have been integral members of the MDSC family, attending Baby Massage classes, becoming regulars at New Family Socials and attending our Buddy Walks to spread awareness and help other families.

In 2015, we enhanced and expanded our signature Parents First Call Program, serving new and expectant families in more ways than ever.

The MDSC trained over 700 health care professionals through participation in Grand Rounds and presentations to OB/GYN departments, genetic counselors, NICUs, and medical students at major hospitals. We organized outreach to all 50 maternity hospitals across Massachusetts.

In addition, we launched a First Call Advisory Council, ensuring best practices within the program, hosted a Spanish-language support group for families of children under 6, and welcomed more than ever before to our huge array of First Call Program offerings: New Family Socials, Baby Massage classes, Complex Needs groups, and Pre-natal Socials.

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.





new and expectant families
received personal one-on-
one support, information
and guidance from our First
Call Program in 2015.

PUBLIC AWARENESS

Taking their Community by Storm

It all started for Jessica and Brian Caprio with a single word they had yet to hear since their newborn son, Dominic, was diagnosed with Down syndrome: "Congratulations!" But there it was: the first word in an MDSC care package and a recurring theme in a phone call from our Parents First Call program.

Before long, the Caprios formed their first Buddy Walk team and got out in their Barnstable community to raise awareness. They connected with family and friends, got active on social media and pulled together an all-weekend bake sale in front of their local Stop & Shop. "We jumped in with both feet," Jessica says.

Their efforts didn't end there. Over the next two years, Jessica and Brian served as chairs of our fledgling Buddy Walk by the Sea, using their deep community connections on Cape Cod to take the event to the next level.

"We felt that our efforts would be giving Dominic the best life possible," Jessica says, citing the MDSC's public policy initiatives, which passed laws like the National Background Check Bill.

Working hand-in-hand with the MDSC, the Caprios and an army of other dedicated Buddy Walk Team Captains across the state raise awareness to change the hearts and minds of people in the community about the immeasurable value of all people with Down syndrome.

"We felt that our efforts would be giving Dominic the best life possible."

- Jessica Caprio

In recent years, the MDSC has made public awareness a top priority, recognizing that people with Down syndrome cannot reach their full potential unless the general public is on board. In 2015, our Buddy Walk Program reached new heights, bringing together 4,400 walkers, the most ever, at three events throughout the state.

In 2015, the MDSC put the finishing touches on Your Next Star, a major web-based, interactive public awareness campaign that will open the eyes of employers to the power of people with Down syndrome in the workplace.



families, self advocates and friends came together at our Buddy Walks to celebrate the lives of people with Down syndrome.



ADVANCING MEDICAL CARE AND RESEARCH

Supporting Critical Research Making a Real Difference

The MDSC's Medical & Scientific Advisory Council (MSAC) carefully vets studies submitted by researchers from around the country. A select few – about a dozen a year – are approved for dissemination to our membership, each holding a promise of making a positive difference for our community, whether in the short- or long-term.

Each study the MSAC approves holds the promise of making a positive difference, whether in the short- or long-term.

For Natalie Lyons, 18, of Northbridge, that promise of improvement came soon after she signed up for Health U., a UMass Medical School weight loss study approved by the MSAC. The program, designed specifically

for young adults with intellectual disabilities, led to the most measurable of improvements for Natalie – the loss of 30 lbs. in a year.

Natalie, the daughter of Kathy and Neal Lyons, had struggled with weight loss for years. But in Health U. she found a program with a uniquely holistic approach which led to her trading in mozzarella sticks for a salad, salt for other spices, and television for a bike.

At last year's Buddy Walk & Harvest Fair, Natalie – supported by friends from Northbridge High School – walked a total of 13,000 steps, according to her pedometer, or nearly 5 miles. "She could never do that before," her mother said.

As with all the MSAC-approved research studies, the MDSC is proud to support critical research like Health U. that is helping people with Down syndrome reach their full potential.



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.



MDSC LEADERSHIP

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