



**CHAMPIONING
ACCEPTANCE,
INCLUSION &
INNOVATION**

MESSAGE FROM OUR LEADERSHIP

Thanks to your support, the Massachusetts Down Syndrome Congress (MDSC) made a significant impact in the lives of people with Down syndrome and their families across the Commonwealth in 2014.

"The MDSC has been on the front lines working on policies to ensure that all people with Down syndrome have opportunities to lead inclusive, fulfilling lives in the community."

Here in Massachusetts, because of the work of all of you, our loved ones with Down syndrome no longer have to live hidden away in the shadows. People with Down syndrome are taking more ownership over all aspects of their lives - education, health care, employment, public policy and recreation.

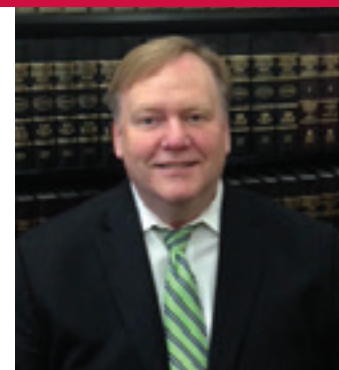
The MDSC has been on the front lines working on policies to ensure that all people with Down

syndrome have opportunities to lead inclusive, fulfilling lives in the community. Three major pieces of legislation - the ABLE Act on the federal level, and the National Background Check and Real Lives bills on the state level - have passed. We are now working with the respective administrations to ensure that these laws are interpreted and implemented with the best interest of our community in mind.

We are working with leaders in the Down syndrome community from across the state and on a national level to strengthen our community so that all families have access to up-to-date information and supports. The commitment of these leaders and groups to working with the MDSC is unparalleled, and we are thrilled about the prospect of generating even more ideas that help us achieve our common goals.



Maureen Gallagher



Steve Narey

In 2015, the MDSC will launch its major public awareness campaign to open the eyes of employers to the power of people with Down syndrome in the workplace. The project includes a web-based campaign or "microsite" focused on employment, a topic that promises to have a significant impact on achieving our mission of ensuring that individuals with Down syndrome in Massachusetts are valued, included and given opportunities to pursue fulfilling lives.

From our membership survey last year, we found a gap in social programs for our self-advocate members after they leave high school. That's why we made a concerted effort to expand social programs and opportunities for adults with Down syndrome. We now have ongoing quarterly socials and educational workshops for adults with Down syndrome. We are also in the process of planning our first ever conference organized specifically for adults with Down syndrome ages 21 and up and their families.

As you know, our Parents First Call Program provides families with one-on-one support, information and resources at a critical and tender time. First Call also includes many other activities to support families year round. New families can get support from the MDSC in a range of ways to meet their needs: quarterly New Family Socials, a support group for

families of children with complex needs, social get-togethers for prenatal families and gatherings for families of diverse backgrounds.

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.

The MDSC launched a series of educational initiatives that has helped dozens of Massachusetts families work more closely and collaboratively with their school's teachers and administrators for the benefit of their child. We have introduced IEP workshops in different regions of the state, a collaborative 6-part early education workshop with the Learning Program and quarterly webinars on a variety of education-related topics.

In the fall of 2014, we published our long-awaited resource guide for elementary educators. Over 600 copies of this guide, "Meaningful Inclusion for Students with Down Syndrome," have been disseminated to educators, parents and others who want to know about the best practices available for educating students with Down syndrome.

We are excited to share that the MDSC Board of Directors will be working to chart our course for the next 5 years by developing a new strategic plan. Thanks to you, we achieved all our goals for our previous strategic plan and now it's time to envision new and exciting goals for the future. The

thoughtful feedback from our membership survey last year will guide us as we go through this process.

The heart and soul of the MDSC continues to be doing whatever it takes to serve our existing members while connecting as early as possible with new members to provide critical support. Our Parents First Call and AIM programs continue to be the bedrock of the MDSC, but as you can see in this report, there is so much more going on at the MDSC. We appreciate your role in helping us build a bright future for the MDSC and the Down syndrome community in Massachusetts.

So many of you, in your own individual way, have helped the MDSC achieve our mission in 2014. Working together, we have had a tremendous impact.

Whether you served in a leadership role, significantly contributed to one of our walks or other events, hosted a community fundraiser, joined our Circle of Giving, or funded a grant for one of our wonderful programs, we salute you for your support.

In closing, we look forward to an exciting journey with you in 2015 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



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.

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 that includes transition planning, and life-long learning.
- To ensure that expectant and new families receive accurate and up-to-date information and desired supports.
- To educate our stakeholders through a clearinghouse of information and resources related to Down syndrome in Massachusetts.
- 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.





CHAMPIONING ACCEPTANCE, INCLUSION & INNOVATION

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 2014, we chose a theme, "Champions!", because we know something that not everyone does. People with Down syndrome and those who love them are champions. It's in the extra chromosome and it's in the nature of having to fight for what we deserve – the opportunity to pursue fulfilling lives.

It's been 30 years since the MDSC formed with humble

beginnings but a vision for a bright future. That future is now, and while it's a vast improvement over a dark past when people with Down syndrome were not accepted into society, we have a long way to go until all our neighbors, doctors, teachers, lawmakers and employers understand the value that each person with Down syndrome brings to the world around us.

As you will see in this report, we may be a statewide organization, but 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.

We have a vision for what our state and country should be like for all people with Down syndrome. With your support, we're getting closer each and every year 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.

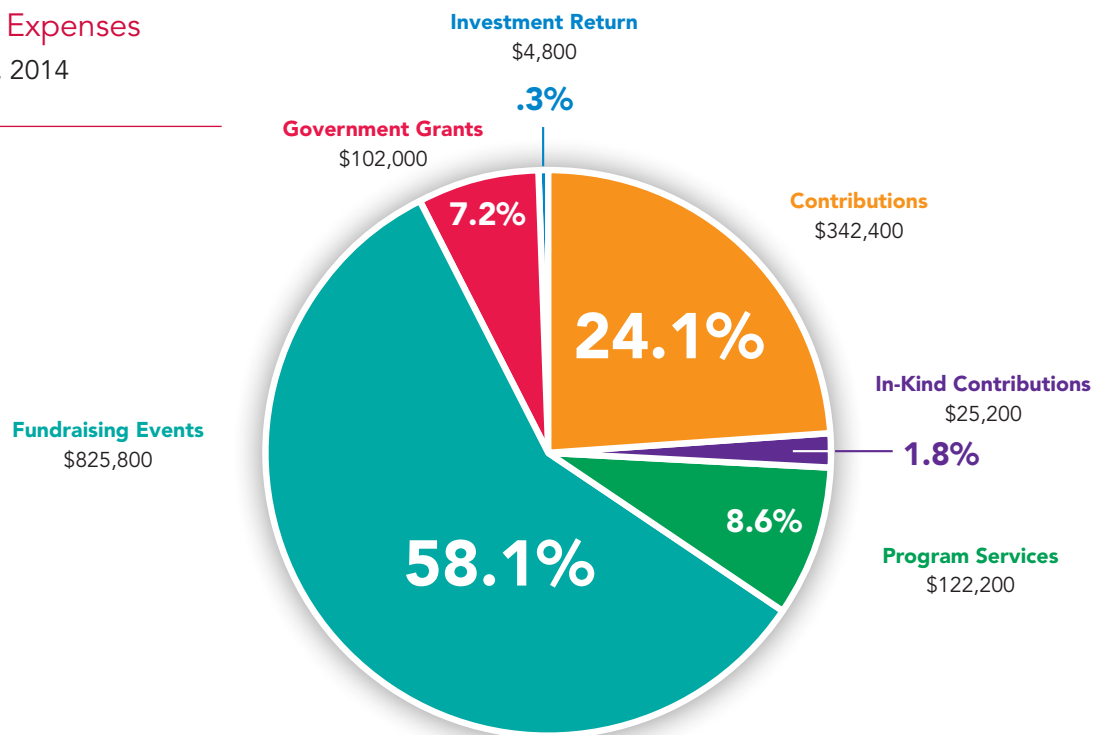
2014 FINANCIAL STATEMENT

Connecting Revenue with Expenses

For Fiscal Year Ending June 30, 2014

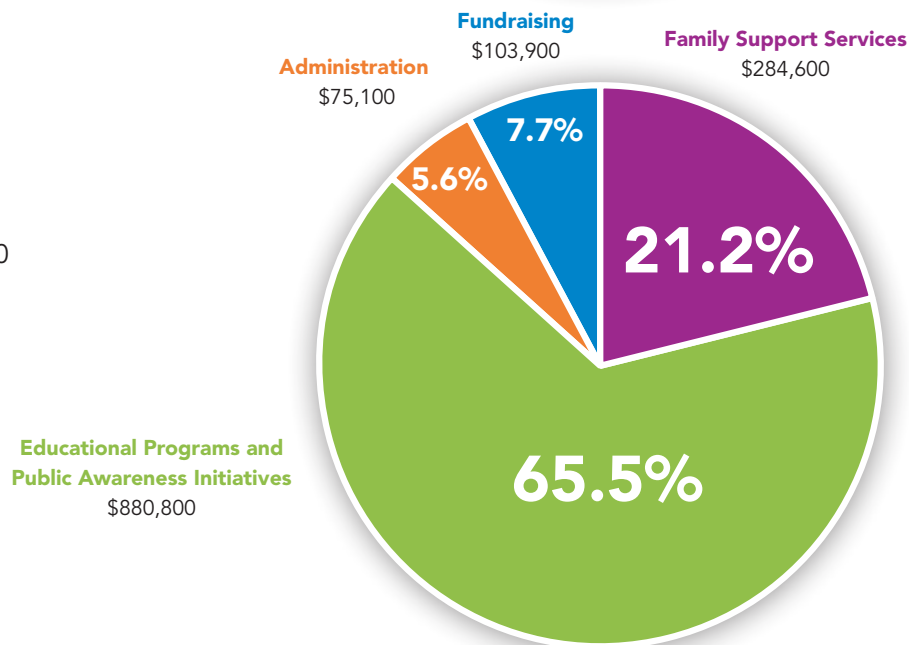
REVENUE

Total Revenue \$1,422,400



EXPENSES

Total Expenses: \$1,344,400





SELF ADVOCATE ADVISORY COUNCIL

Building Confidence, Leadership, Friendship

Before the MDSC, John Dunleavy already seemed to have it all – a job with the Bruins, a loving family and a hometown that embraced and supported him.

But his parents knew that appearances can be deceiving. Something was missing – confidence, leadership skills, peer friendships; things that are critical in life.

“The SAAC is giving self advocates like John opportunities to connect and lead.”

So John joined the MDSC Self Advocate Advisory Council. “Reserved and quiet” in his first few meetings, the transition was, well, a transition. But before long, remembers Colleen Endres, who runs the program, John “came out of his shell.”

Ever since, not only has John rocketed skyward on the Council and in life, he hasn’t even bothered to look back. He has served as

honorary coach for the Boston Bruins Alumni team... twice. He has delivered a keynote address at the MDSC Annual Conference. And he was even invited by Bruins coach Claude Julian to give his team a pre-game pep talk.

John is now a confident young man, speaking up for himself and others.

90

adults with Down syndrome joined new networking and social events organized by self advocates for self advocates.

Just as John’s ambitions are expanding, so is the Council’s. The SAAC is giving self advocates like John opportunities to 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 Impacts

For Katie DeVellis, politics isn't just sport – it's her life.

Now 20 years old and attending a day school, Katie had been unable to save for life after graduation because of outdated laws that would penalize her family. "We didn't have a tax-free way to save like we did with the other kids," said Katie's mom, Ann, who has four daughters.

So what did Katie and Ann do? They joined up with the MDSC's delegation that travels to Washington, D.C. to fix injustices like this. Last year, after intense lobbying by Katie, Ann, and hundreds of others, Congress passed the ABLE Act, a landmark bill that will finally allow people with disabilities to save like everyone else.

For Ann, the ABLE Act's passage is a bit late – "I wish we could have started saving earlier, it would have been easier." But their efforts, combined with the expertise and guidance of the MDSC is making a real difference, if not for themselves, for the tens of thousands of families across the country who will follow in their footsteps.

Now, in a matter of a couple of years, Katie and Ann have gone from timid advocates to seasoned policy veterans. Katie may be naturally shy but when she sits down with a lawmaker or their staff, she knows it's her turn to give her two cents. "It's a real sense of accomplishment," Ann says.

*"We didn't
have a tax-free
way to save for
Katie like we
did with the
other kids."*

- Ann Kelly

In 2014, the MDSC became even more of a major player in state and national disability public policy. For the first time in our history, we hosted an advocacy day at the state house where our self advocates and their families came together to inform policy makers about progressive legislation that could change their lives. Together, we successfully lobbied for the Real Lives Bill and the National Background Check Bill, two far-reaching pieces of legislation. We may have been the only state in the country whose entire Congressional delegation was signed on to the ABLE Act, and the MDSC was leading the charge.



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





EDUCATION

Getting Parents & Schools the Resources They Need

As Megan Sanphy got deeper into her elementary education, her parents realized they needed help. They knew instinctively that an inclusive education was best for their beautiful 7-year-old daughter, but they were at a loss – how do they work with Megan’s school to make inclusion a reality.

“Michele and Matt discovered that reaching out to the MDSC means that the MDSC reaches right back out to them.”

So Michele and Matt Sanphy turned to the MDSC and our 30-plus years of expertise in the field. They found in us a wealth of resources, starting with the three W’s – our website, workshops and webinars. Webinars like, “How to Work Effectively With Your IEP Team,” helped them in the most concrete of ways.

Michele and Matt also discovered that reaching out to the MDSC means that the MDSC reaches right back out to them. By connecting directly with our Education Director, they learned firsthand about what constitutes a “least restrictive environment” and what they are guaranteed by law. And Michele and Matt directed Megan’s teachers to our educator resources, including our Annual Educators Forum and Annual Conference, so that they could learn directly from experts in their own field.

Ultimately, the Sanphys got exactly what they needed from the MDSC: “invaluable” information that helped them and their school ensure that Megan got the best possible education.

1,205 General and special educators, paraprofessionals, administrators, specialists and parents learned best practices in educating students with Down syndrome at MDSC webinars, workshops and our two major conferences, the Educators Forum and the Annual Conference.

The list of resources the MDSC has to support families and educators expanded in 2014. Thousands of families in Massachusetts and beyond took advantage of our education-related workshops, webpages and conferences in 2014, and the MDSC helped many others access scholarly articles, legal rulings, and referrals to partner organizations that were critical to helping them navigate the system.

In 2014, we launched a special education webinar series to address challenging topics in the field of disability education. And our Education Task Force published “Meaningful Inclusion for Students with Down Syndrome: An Educator’s Guide,” a comprehensive manual that covers best practices for educating students with Down syndrome.





Photo by Mark Hunt

ADVOCATES IN MOTION

Interpersonal and Intellectual - Striking the Balance

Cheerful and outgoing, 10-year-old Omar Masood had a lot going for him when he moved to the Bay State in 2007. He had plenty of hobbies – horseback riding, movies, swimming, baseball and a loving, supportive family.

But he also had significant challenges, having struggled to make new friends as he relocated from California to Florida to Massachusetts over the years... and having Down syndrome.

"Kids with disabilities have very little chance to interact with other people outside of school," Omar's dad said.

So, even before he was 13, his parents signed Omar up for A.I.M, the MDSC's Advocates in Motion program. A.I.M. brings together teens and young adults with and without Down syndrome to connect with one another, develop friendships, and learn about how to become more active in their communities.

"Sports is Sports," his dad said, but Omar needed true peers and the intellectual stimulation that comes with interacting with like-minded people. A.I.M. has struck the perfect balance of the interpersonal with the intellectual, making it a national model today.

Most people just take the camaraderie of their friendships for granted. But not Omar and the hundreds of others who have benefited from our Advocates in Motion Program since its inception in 2008.

Today, Omar is 18, and "A.I.M. has been instrumental in helping him develop into a very sweet caring, grown up," his dad said. "It's a place he belongs."

"A.I.M. has been instrumental in helping Omar develop into a very sweet caring, grown up. It's a place he belongs."

- Sohail Masood

In 2014, 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. The program delves into a health-focused curriculum at events with titles like How to be Healthy in a World Full of Stress, Communicating our Health Needs and Making Good Choices.



202

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



PARENTS FIRST CALL

Changing Lives One Family at a Time

Sharon Romeo grew up adoring her cousin with Down syndrome. So when she realized at birth that her daughter Sofia had Down syndrome too, you might think she'd be fine with it. She wasn't. "Our grief overwhelmed us," recalled Sharon.

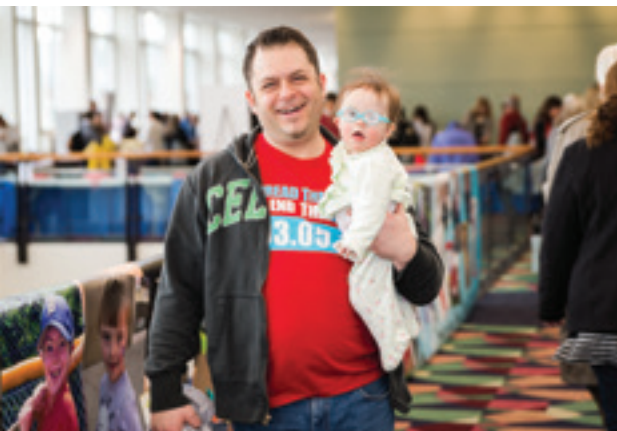
"We don't know what we would do without the MDSC."

- Sharon Romeo

Sharon and her husband Michael initially retreated from supports, but when they were ready to engage, the MDSC was there. Today, Sharon and her husband haven't looked back. They have made every quarterly New Family Social, our Baby Massage class, and two Buddy Walk & Family Festivals.

Not only is Sofia thriving, but Sharon and Michael say they couldn't be luckier to have stumbled into a warm, generous community.

"We don't know what we would do without the MDSC," Sharon said.



In 2014, we reshaped our Parents First Call Program, serving more expectant families in more ways than ever.

The MDSC trained 729 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. And 127 letters on healthcare guidelines were distributed to physicians across the state.

In addition, we brought in a genetic counselor to provide supports to the peer mentors who work with our families, expanded our New Family Socials to ensure that new parents have every opportunity to meet with others in their shoes, and branched out to host other kinds of events, from Baby Massage classes to Complex Needs groups. For the first time ever, we brought together expectant parents for a Pre-natal Social, something that would have been unimaginable just a few years ago.

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.

145 new and expectant families received personal one-on-one support, information and guidance from our First Call Program in 2014



Photo by Melanie Perkins McLaughlin

PUBLIC AWARENESS

Building Capacity to Change Hearts & Minds

Roxanne Hoke Chandler and her daughter Faith are a walking, breathing Down syndrome public awareness campaign.

With their color-coordinated “Got Faith?” sweatshirts, Faith’s disarming smile and Roxanne’s heart-on-her sleeve passion, the mother-daughter duo are easy to spot. And everywhere they go, they are on the front lines of the MDSC’s efforts to spread the word about the beauty and abilities of people with Down syndrome.

The MDSC’s grassroots public awareness efforts go hand-in-hand with Roxanne’s efforts to give Faith the best life possible. The MDSC offers our message of empowerment, and Roxanne takes this message to the streets, with her particular focus on communities of color.

On Facebook, Twitter and YouTube, Roxanne shatters stereotypes by sharing MDSC posts with her network. And her unmatched personal recruitment efforts help bring families under the MDSC umbrella. Together, the MDSC and Roxanne are working the trenches of our shared war on ignorance.

Roxanne’s personal touch has been so successful that she can now be found at the Buddy Walk & Family Festival with a crew of about 40. “We’re always at the same spot [on Wakefield Common], right under the big tree.”

While the MDSC is building our capacity to reach a broader audience, Roxanne and Faith are out there changing hearts and minds one person at a time. Together, we are making a real difference.

“Massachusetts is the place to be for people with Down syndrome,” she says.

“The MDSC’s grassroots public awareness efforts go hand-in-hand with Roxanne’s efforts to give Faith the best life possible.”

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. For the first time, in Fiscal Year 2014, the MDSC held three Buddy Walks throughout the state. The Wakefield walk, which celebrated its 19th year, took on a more muscular identity - from “Family Picnic” to “Family Festival.”

The MDSC launched a Buddy Walk Celebrity Ambassador campaign that put people like Captain America star Chris Evans, Olympic gold medalist Aly Raisman and Glee actress Lauren Potter on film pitching for the MDSC. And, we began work on a major web-based public awareness campaign that aims to open the eyes of employers to the power of people with Down syndrome in the workplace.



4,300

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



ADVANCING MEDICAL CARE AND RESEARCH

Keeping a Pulse on the Latest Advancements

In the summer of 2013, we got an email from a researcher named Dr. Jeanne Lawrence at the University of Massachusetts Medical School. For two years prior, an MDSC team made up of a physician, a self advocate and our Family Support director had visited Dr. Lawrence's class to give her medical students a more personal understanding of Down syndrome.

"Overnight, Dr. Lawrence had become an international star, but we wanted our members to have the chance to hear from her directly... and ask their questions. "

But the email was not about Dr. Lawrence's class. It was about her research, and some major news that was about to break. The journal *Nature* was going to publish a paper by her team proving that the genes causing

Down syndrome could be silenced in a laboratory. They were findings that would shake our Down syndrome community to the core.

Because of our direct connection to the researchers, the MDSC was the first Down syndrome organization in the country to find out about and respond to the development. In a message from our executive director, we put the study results in context for our members and offered support for our families.

And we didn't stop there. We knew our members would be hungry for any and all information that impacts their loved ones – even information as dense and challenging as cell biology research, so we reached back out to Dr. Lawrence. Overnight, she had become an international star in great demand, but we wanted our members to have the chance to hear from her directly...and ask their questions.

The following March, at our 30th Annual Conference in Worcester, Dr. Lawrence presented her findings, explaining her concept that "gene imbalance across an extra chromosome can be de facto corrected by manipulating a single gene." It was a standing-room only crowd.



Our efforts in the area of medical care and research are deep and broad. We educate health care 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 share with members. We facilitate communication between health care 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.

729

Health care professionals
received up-to-date
accurate information
about Down syndrome
through MDSC medical
outreach programs.



Protein

MDSC LEADERSHIP

MDSC Board of Directors

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Sarah Cullen Family Support Director	Elaine Crowley Administrative Coordinator	Mychelle Lee Program Specialist
Joshua Komyerov Communications & Operations Director	Jacquie Sherman Executive Assistant	Ashley Coates Teen and Adult Services Facilitator
Mo Blazejewski Education Director	Becca Canavan Development Director	

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