2014 Annual Report

CHAMPIONING ACCEPTANCE, INCLUSION, & INNOVATION

THE WORLD IS OURS
Mission Statement

To ensure individuals with Down syndrome in Massachusetts are valued, included, and given 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.
Overview

• Financial Status
• Program Highlights
• Strategic Planning
2014 FINANCIAL STATEMENT

Connecting Revenue with Expenses

For Fiscal Year Ending June 30, 2014

REVENUE

Total Revenue $1,422,400

Investment Return
$4,800

.3%

Government Grants
$102,000

7.2%

Contributions
$342,400

24.1%

In-Kind Contributions
$25,200

1.8%

Fundraising Events
$825,800

58.1%

Program Services
$122,200

8.6%
2014 FINANCIAL STATEMENT
Connecting Revenue with Expenses
For Fiscal Year Ending June 30, 2014

EXPENSES
Total Expenses: $1,344,400

- **Administration**: $75,100
- **Fundraising**: $103,900 (7.7%)
- **Family Support Services**: $284,600
- **Educational Programs and Public Awareness Initiatives**: $880,800 (65.5%)
Self Advocate Advisory Council

Building Confidence, Leadership and Friendship

- 13 SAAC Council members advise MDSC on issues of importance
- Developing social network for adults
- New adult conference in collaboration with MGH on Oct. 24, 2015

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

Systemic Change with Real-World Impacts

• Hosted first Down Syndrome Advocacy Day at the State House
• Sent delegation to the Buddy Walk on Washington
• Passed our three priority bills
  ✓ NBC Bill
  ✓ Real Lives Bill
  ✓ Able Act
Education

Getting Parents and Schools the Information They Need

- Educators Form
- Annual Conference
- Partnership with The Learning Program
- Webinars
- Regional Meetings
- Education manual

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 WORLD IS OURS
Advocates in Motion

Developing leadership, life skills and friendship

- Provides fun, inclusive, interactive events each month for young people with Down syndrome and their peers (ages 13-22).
- Fosters social relationships among program participants while simultaneously providing exposure to some of the following: fitness/healthy lifestyles, community service experiences, job and career skill building, sports and the arts.
Parents First Call
Changing Lives One Family at a Time

- Provides information, support and guidance to new and expectant parents after their child is diagnosed with Down syndrome.
- 50 trained First Call parent volunteers provided support to 145 parents in FY14.

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

THE WORLD IS OURS
Prenatal Outreach

• New non-invasive prenatal blood test, administered during the first trimester of pregnancy, was released by Sequenom in the fall of 2011. There are now additional companies that are marketing these tests including: Ariosa, Illumina (Verinata), Natera, MaterniT21 and Panorama.

• The MDSC is proactively stepping up efforts to provide expectant couples with accurate, up-to-date information.

• Eleven specially trained First Call parents provided support to 27 prenatal families in FY14.
Statistics

• Recent studies indicate that one in every 830 babies is born with Down syndrome each year in the United States.

• This translates to approximately 85 babies born each year in Massachusetts.
• Organizations from across the United States are turning to the MDSC for guidance on how to start their own First Call program.

• MDSC Family Support Director, Sarah Cullen, has provided replication training to organizations in 11 states including: Michigan, North Dakota, Louisiana, Connecticut, Vermont, North Carolina, New Hampshire, Pennsylvania, Texas, Virginia and California.
Collaborations and Support Groups

Expanding Our Reach

• MDSC and MGH co-host a new quarterly group for Spanish-speaking families
• MDSC and Boston Children’s Hospital co-host a quarterly group for families of children with complex needs.
• New Family Socials are hosted at the MDSC office.
• DADs and Down Syndrome Autism Connection Affiliates
• MDSC and Mass Families Organizing for Change host monthly workshops on transition related topics such as housing.
• MDSC collaborates with other local DS groups across the state to ensure families have opportunities to connect with local families. We recently hosted our second annual support group leadership retreat to help local groups to connect with one another.
• Grandparent groups.
Public Awareness
Building Capacity to Change Hearts and Minds

• Three buddy walks *Making a World of Difference*
• Celebrity ambassadors
• The power of social media
• New public awareness campaign focused on employment

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 Accomplishments

• MDSC Medical and Scientific Advisory Council
• Educating health care professionals
• Operation House Call
• Approved 8 studies for MDSC members to consider participating in
MDSC Membership Growth
MDSC Strategic Plan

• Current 5 year plan effective through 2015
• MDSC Board developing new strategic plan for the 2016-2020 time period
• Looking at serving people with Down syndrome and their families across the lifespan
• Your feedback from our membership survey is valuable to help us vision our future.
Questions and Answers?
GOVERNANCE COMMITTEE
REPORT

MDSC Governance
Committee Chair

Louise Borke
RENEWING
BOARD MEMBERS

Louise Borke
Steve Narey
Margaret Pulsifer
David Southworth
NEW BOARD MEMBERS

Election of New Board Members

David Falcone

Bill Fitzgerald
RETIRING BOARD MEMBERS

Special Thanks

John Nadworny
Beverly Beckham
Closing Remarks

Steve Narey, Board Chair