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MARCH

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ANNUAL MEETING PRESENTATION REAL LIVES

Welcome
Maureen Gallagher
MDSC Executive Director



ANNUAL MEETING REPORT

- Program Highlights
 - Membership Update
 - Capacity Building
 - Financial Status
 - Strategic Direction
-

Program Highlights



PARENTS' FIRST CALL

- Provides information, support and guidance to new and expectant parents after their child is diagnosed with Down syndrome.
- 46 trained First Call parent volunteers provided support to 126 parents in FY12.

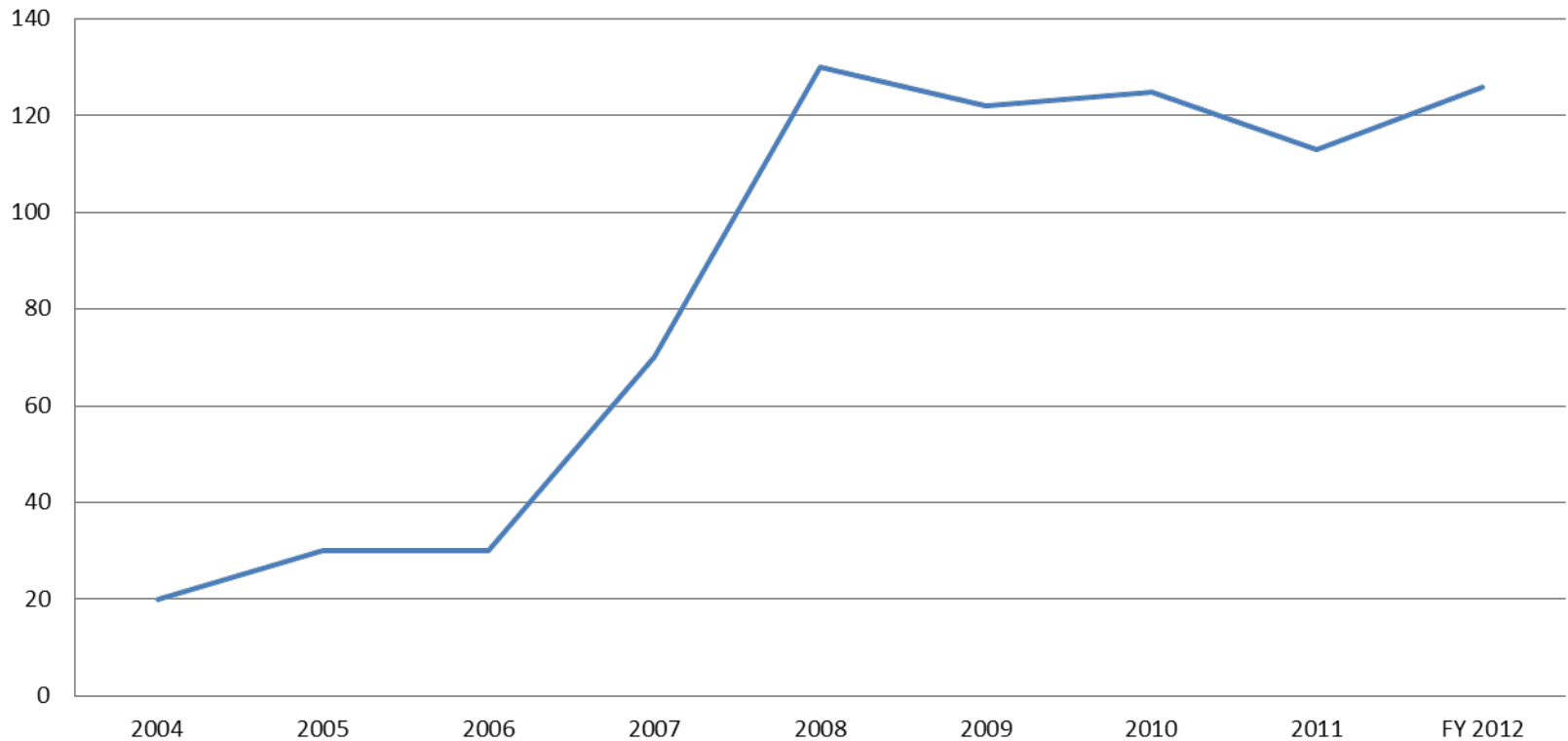


UPDATED STATISTICS

- Recent studies indicate that one in every 830 babies is born with Down syndrome each year in the United States.
- This translates to approximately 90-95 babies born each year in Massachusetts.

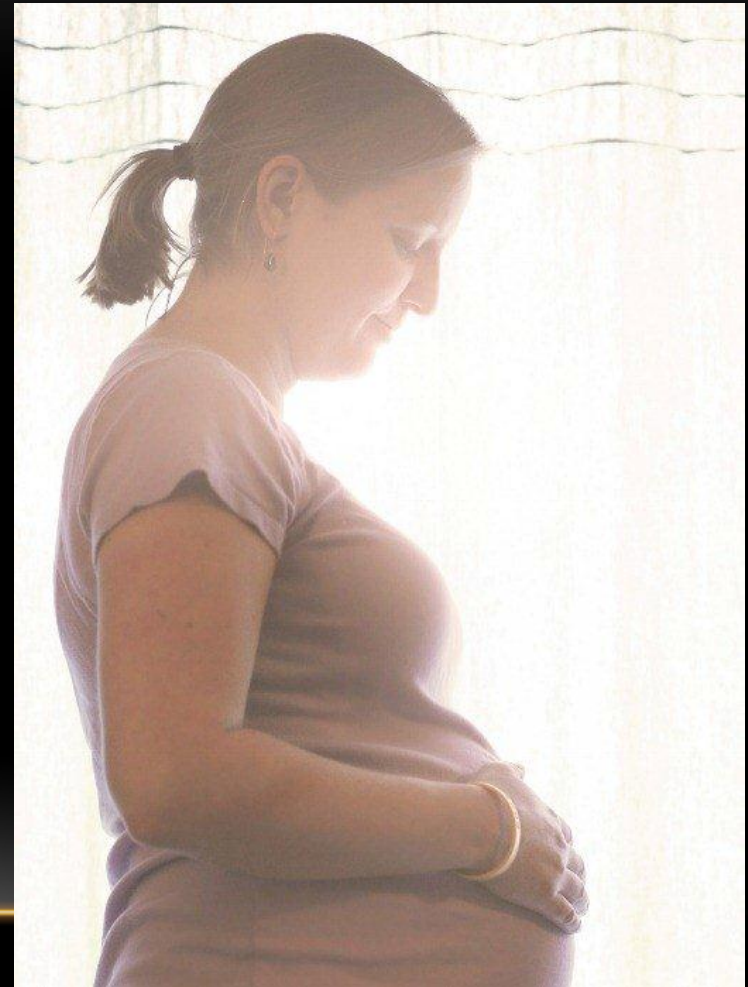
126 POSTNATAL FAMILIES SERVED IN FY2012 FIRST CALL PROGRAM

Postnatal Families Served

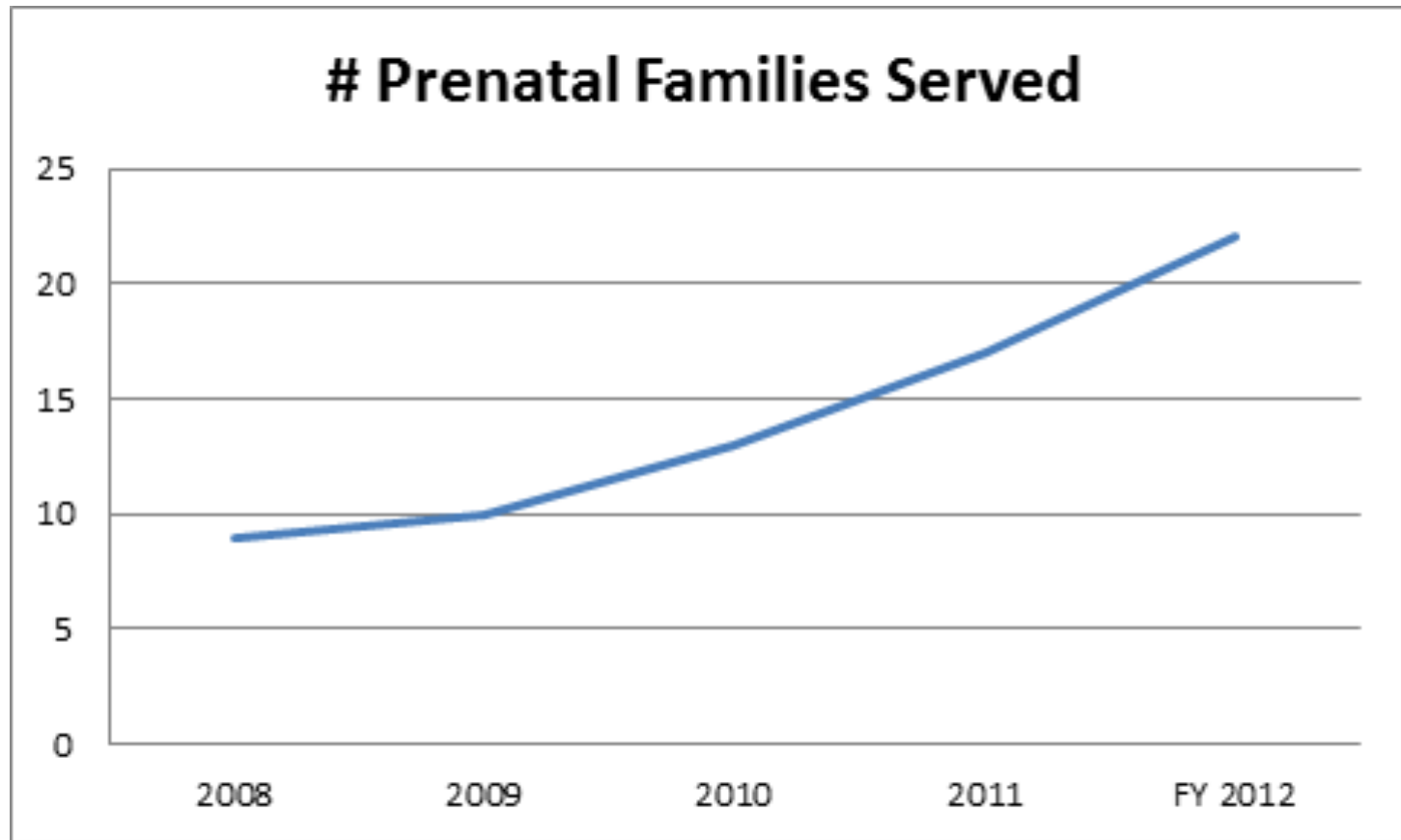


PRENATAL OUTREACH

- 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 3 additional companies that are marketing these tests including: Ariosa, Illumina (Verinata), and Natera.
- The MDSC is proactively stepping up efforts to provide expectant couples with accurate, up-to-date information.
- Six specially trained First Call parents provided support to 22 prenatal families in FY12.



22 PRENATAL FAMILIES SERVED IN FY2012 FIRST CALL

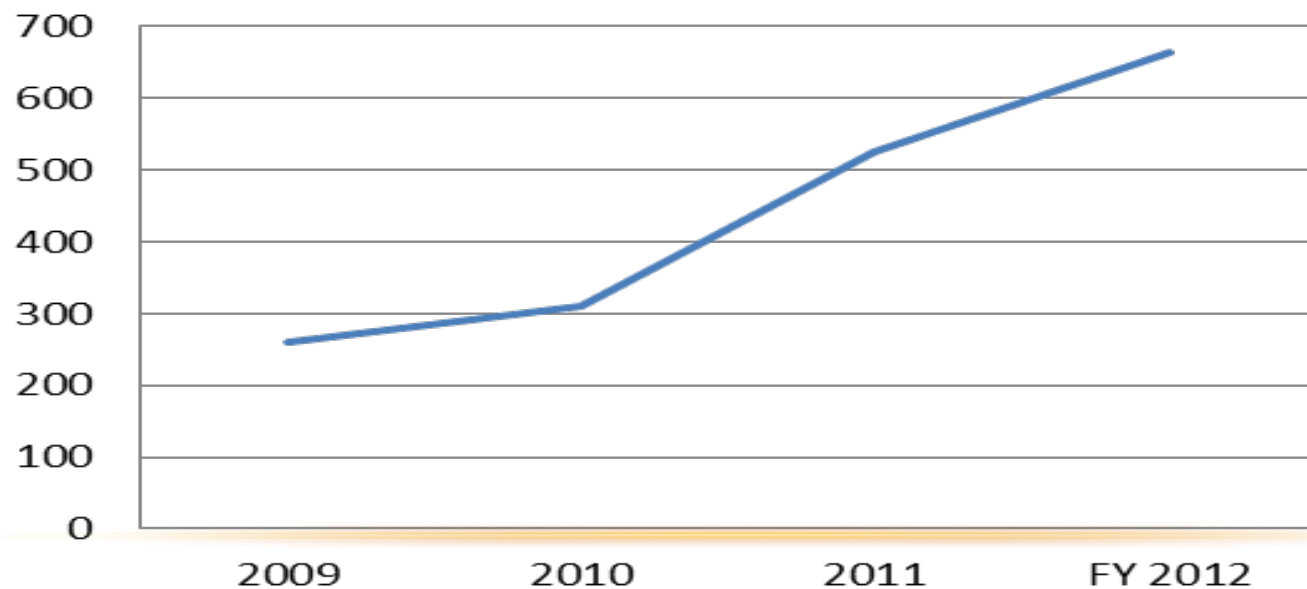


COMMUNITY OUTREACH AND EDUCATION

- Trained over 665 health care professionals through participation in Grand Rounds and presentations to OB/GYN departments, genetic counselors, NICU's, and medical students at major hospitals.
- Organized outreach to all 50 maternity hospitals across Massachusetts.
- 126 letters on healthcare guidelines were distributed to physicians.
- New collaboration with Operation House Call.



Attendees at Medical Presentations



FIRST CALL PROGRAM - NOW A NATIONAL MODEL

- 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 technical support to organizations in 7 states including: Michigan, North Dakota, Louisiana, Connecticut, Vermont, North Carolina, and Pennsylvania.

D.A.D.S.

- Joined the MDSC as an affiliate in 2009 and has grown to serving close to 400 fathers of children with Down syndrome.
- DADS organizes monthly meetings, family outings, and fundraising events.



DOWN SYNDROME AUTISM CONNECTION

- Joined as an affiliate of the MDSC in 2011 to ensure that families who have children with a dual diagnosis have access to the information and resources they need.
- Monthly online chats are hosted for 58 families who have joined this group.



GRANDPARENT GROUP

- Our grandparent network allows grandmothers and grandfathers to connect with each other and share stories, resources and support.
- The group is coordinated by grandmother, Regina Kando and connects primarily through an online listserv.



NEW GROUPS & COLLABORATIONS TO EXPAND OUR REACH

- MDSC and Boston Children's Hospital co-host a new group for families of children with complex needs.
 - New Family Socials are hosted at the MDSC office.
 - MDSC and Mass Families Organizing for Change host monthly workshops on transition related topics such as housing.
-

ADVOCATES IN MOTION PROGRAM (AIM)

- 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.
- 170 young people participated in AIM activities during FY12.

AIM HOLIDAY PARTY



SELF-ADVOCATE ADVISORY COUNCIL

- Self-advocate advisory council guides the MDSC on the needs of adults living with Down syndrome.
- The SAAC is open to any adult with Down syndrome 21 years old and older who has an interest in developing leadership and self-advocacy skills.
- Members of the Council serve at least two years.
- Planned first adult social networking event for adults 21 and up with 65 people attending.



LEGISLATIVE ADVOCACY

- MDSC advocated on both a local and national level for policies and legislation to improve the lives of people with Down syndrome.
- Testified at hearings in support of our priority policies.
- Met with key legislators on Beacon Hill and on Capitol Hill to enlist their support of our statewide and national platforms.
- You can support the MDSC Legislative Advocacy Task Force by contacting us at timetospeakout@mdsc.org.



OUR WORK LED TO THE PASSAGE OF TWO CRITICAL PIECES OF LEGISLATION IN FY12

- **H3825 An Act Relative to Down Syndrome Genetic Test Results – Signed into Law on June 22, 2012**

This new legislation ensures that accurate up-to-date information about Down syndrome is available to health care providers who render prenatal care, postnatal care or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down syndrome.

- **HB3720: An Act to Promote the Successful Transition of Students with Disabilities to Post-Secondary Education, Employment, and Independent Living – Signed into Law on March 9, 2012**

This bill ensures a more effective manner, assisting older students with disabilities to receive essential special education transition planning and services necessary to prepare for post-secondary education, employment, and independent living. Requires the Board of Education to provide a mechanism for current special education teachers and rehabilitation counselors to obtain a Specialist Teacher License in Transition Services.

**MDSC' S FIRST PIECE OF LEGISLATION SIGNED
INTO LAW BY GOVERNOR PATRICK
JUNE 22, 1012**



MDSC LEGISLATIVE PLATFORM

PRIORITY BILLS FOR 2013-2014

- **HB1674 National Background Check Bill**

This bill will require national criminal background checks of candidates who apply for positions to work with individuals with intellectual and developmental disabilities served by the MA Department of Developmental Services (DDS).

- **HB151: An Act relative to Real Lives**

This bill redirects the way funds are appropriated for individuals with intellectual and developmental disabilities to develop a support system that both increases quality and on average reduces costs whenever possible. It requires that the Executive Office of Human Services will implement a new home and community based services program to allow public funds to be used as flexibly as possible by the individual.

LEGISLATIVE ADVOCACY NATIONAL PRIORITIES

- **Increasing Co-Sponsors for the Achieving a Better Life Experience (ABLE) Act – the ABLE Act will give individuals with disabilities and their families the ability to save for their child's future.**
- **We successfully secured all MA legislators to sponsor the bill in 2012.**
- **The bill has been reintroduced and we are now asking our legislators to sign on again.**



EDUCATIONAL PROGRAMS

- Hosted Educators Forum for 320 educators and others at the College of the Holy Cross in November of FY12 to teach best practices in including children with Down syndrome in general education.
- Hosted the 28th Annual Conference at the DCU Center for 570 parents, self-advocates, brothers and sisters, educators and others.



EDUCATION TASK FORCE

- Guides the MDSC on education related issues and provides resources to educators and families on best practices.
- Two major projects -
 - 1) The Educator's Manual will be a resource guide of best practices for educating students with Down syndrome.
 - 2) The Teacher Partnership Network matched 10 experienced educators with other educators who have students with Down syndrome in their classrooms.



RESEARCH

LAUNCHED NEW MEDICAL AND SCIENTIFIC ADVISORY COUNCIL

- In FY12 the MDSC launched a new Medical and Scientific Advisory Council to ensure that the MDSC membership has access to accurate up-to-date medical and scientific information and resources pertaining to Down syndrome.
- The Council facilitates communication amongst health care providers and scientists in Massachusetts who are interested in working together to develop best practices in providing medical care, therapies, and research related to Down syndrome.
- Dr. Brian Skotko chairs and council that is comprised of 11 of the most prestigious Down syndrome experts in the region.
- The Council reviewed and approved 6 research projects that were presented to the MDSC membership to participate in.

PUBLIC AWARENESS

- Celebrated National Down Syndrome Awareness Month in October with over 3,500 people gathering for our Buddy Walk at Lake Quannapowitt in Wakefield.
- Worked with Governor Patrick's office to secure a Proclamation for October as Down Syndrome Awareness Month in the Commonwealth of MA.
- Collaborated with the Boston Bruins, John Hancock, and the Falmouth Road Race Committee to raise awareness and funds.



Watch
Video

PUBLIC AWARENESS

(CONT.)

- Promoted awareness through working with the media and boosting online presence which resulted in more than 40 pieces in newspapers and on radio, television and news websites.
- Coverage included: Chronicle, TIME Magazine, CNBC Online, Yahoo! News, Fox 25, U.S. News & World Report, WCVB-TV, Boston Globe, Boston Magazine, Metrowest Daily News, WODS 103.3, Worcester Telegram, Patriot Ledger.



[Watch Video
here](#)


CHRONICLE FEATURED THE MOST IN-DEPTH PIECE EVER SEEN ON PRIME TIME TELEVISION





Individuals with Down Syndrome are fighting for the right to determine their future.

POST A
COMMENT

SOCIAL MEDIA PRESENCE/INTEGRATION


facebook   Search for people, places and things  Massachusetts Down S


Admin Panel  Edit Page  Build Audience  Help  Hide

Notifications  See All

 Gina Carrera, Melanie Perkins McLaughlin and 3 other people like Massachusetts Down Syndrome Congress (MDSC)'s link: "Want to meet new Massachusetts..." 14 hours ago

 Cindy Olson Dufield likes Massachusetts Down Syndrome Congress (MDSC)'s link: "RSVP TODAY! SAAC New Year Bash..." 22 hours ago

 Fiona McGarry likes Massachusetts Down Syndrome Congress (MDSC)'s link: "Thank you Daniel for speaking up..." on Thursday

 Denice Couture-Lafond commented on Massachusetts Down Syndrome Congress (MDSC)'s photo: "so precious they are" on Thursday 

New Likes  See All

 Missy Morgan 4 hours ago

 Renato Carrera 8 hours ago

 Leda Bear 11 hours ago


 Cindy Olson Dufield 22 hours ago

Insights  See All


 Your Posts  Talking About This  Reach



Messages  See All

 Sandy Williams LoPilato Tyngsborough and only via facebook.

 Kat Newland Thank you so much Josh. I can't say en...

 Dennis Evans  Saw this on one of the fitness pages L...


 HeathCliff Rothman  We love the LOVE in this video. We i...


 Jacqueline Davis  www.facebook.com/GetUllianOnEllen


Invite Friends

 Kim Iripp Legendre  Invite 


 Russell Trotter  Invite 

 Colleen Endres  Invite 

 Sara Hart Weir  Invite 










Massachusetts Down Syndrome Congress (MDSC) 

1,628 likes · 156 talking about this · 39 were here

Disability Services
The Massachusetts Down Syndrome Congress (MDSC), established in 1983, began as a non-profit organization made up of parents, professionals and anyone interested

About  Photos  Give to the MDSC  Join Our Email List  Likes 1,628 


 MDSC Tweets
TheMDSC

TheMDSC FREE webinar tomorrow on Social Security Disability: Tools & Tips to Self-Sufficiency! Watch this free webinar... fb.me/1hAIHiR9Z
2 hours ago · reply · retweet · favorite

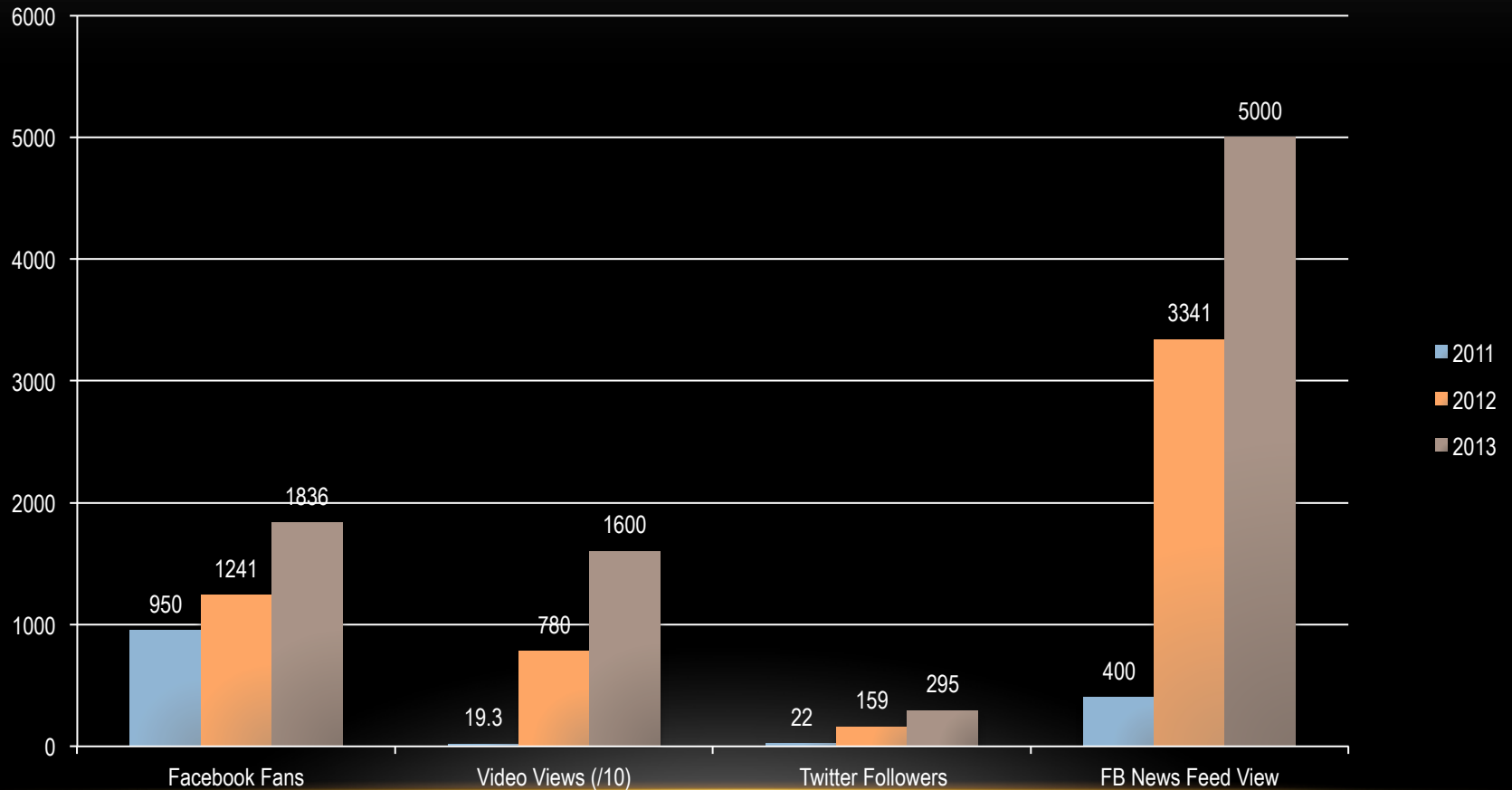
TheMDSC CALL FOR HOUSING PHOTOS: We are putting together a Housing Resources page and need some photos of self-advocates... fb.me/25xixwDEF
3 days ago · reply · retweet · favorite

TheMDSC Join D.A.D.S. on Wednesday, Jan. 9 at 7pm at Mick Morgan's Restaurant in Sharon (973 Providence Highway, Route 1).... fb.me/zVjam1gH
3 days ago · reply · retweet · favorite

TheMDSC Are you a parent of a child with Down syndrome under 2 and looking to meet others like you? Bring your family to... fb.me/2H4Zvn3rL
3 days ago · reply · retweet · favorite

 Join the conversation

INCREASING AWARENESS THROUGH SOCIAL MEDIA



WEBSITE



- Half-a-dozen new Website pages
- Constantly updated Carousel images
- Updated content & links
- Twitter feed on all pages (except homepage)

E-COMMUNICATIONS



- Regular issues of UpSide Weekly
- Other Special Communications



- Event Announcements (Registration Openings, Early Bird Expiring, Speaker Spotlight, Special Guests Bios, etc.)

Awareness Events

Promoted events (2 Buddy Walks, Ed Conference, Marathon, Bruins game, Annual Conference, Fenway Disability Awareness Night, etc.), across platforms



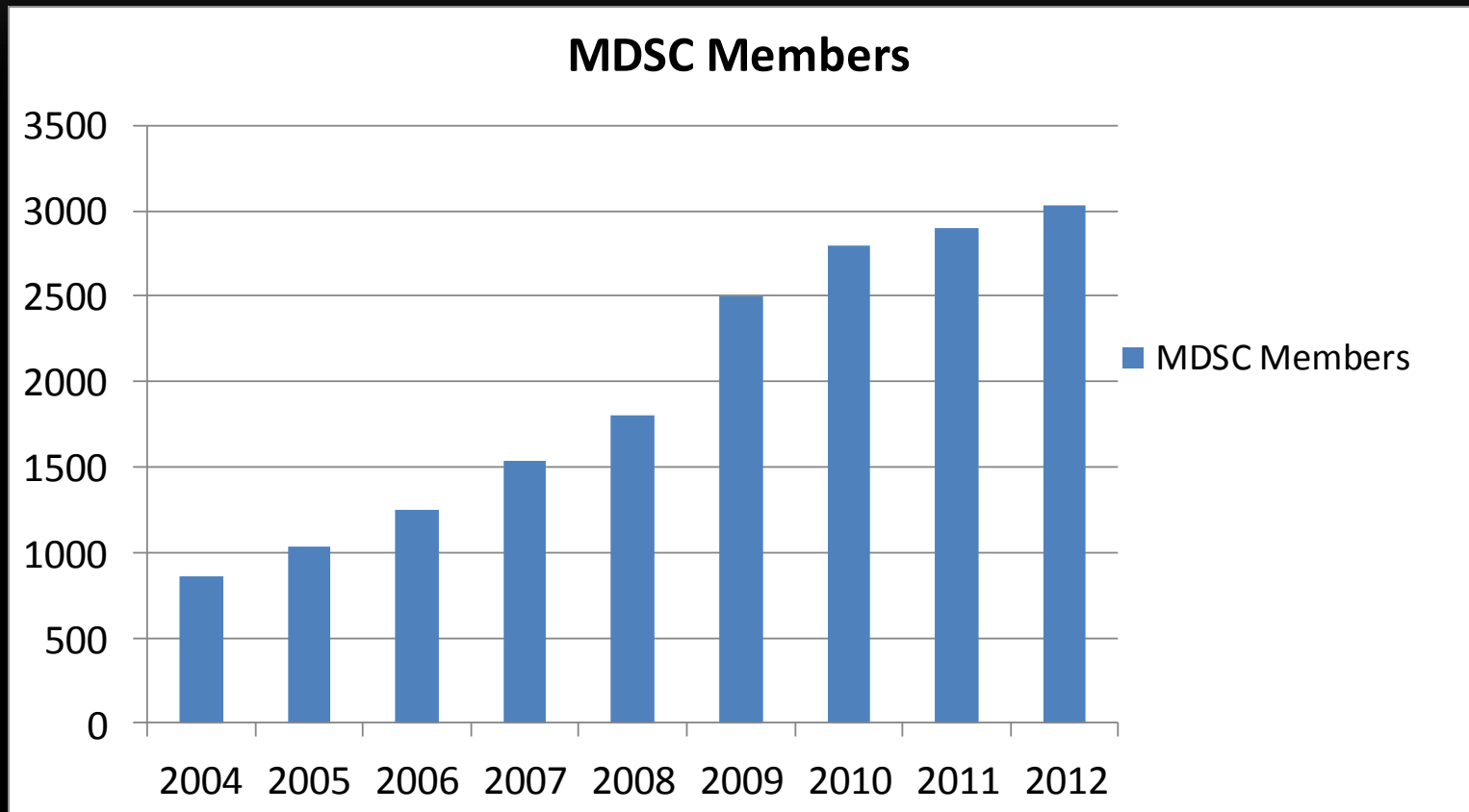
Membership Update



MEMBERSHIP SERVICES

- MDSC is a membership based organization comprised of: Parents, Self-Advocates, Family Members, Professionals, and Community Members who are committed to the MDSC Mission.
- A new membership survey is being developed and will be disseminated in the Spring of 2013. The information collected will serve as a guide for the organizations future growth.
- Our 800 number is staffed 7 days a week by our Family Support Director.
- Our Newsletter keeps members abreast of MDSC activities as well as information about Down syndrome. Sign up now for our listserv (www.mdsc.org) so you can receive our Online Weekly Update.
- Members are encouraged to serve on our many Task Forces. Please contact MDSC if you would like to volunteer.

MDSC MEMBERSHIP GROWTH



Capacity Building

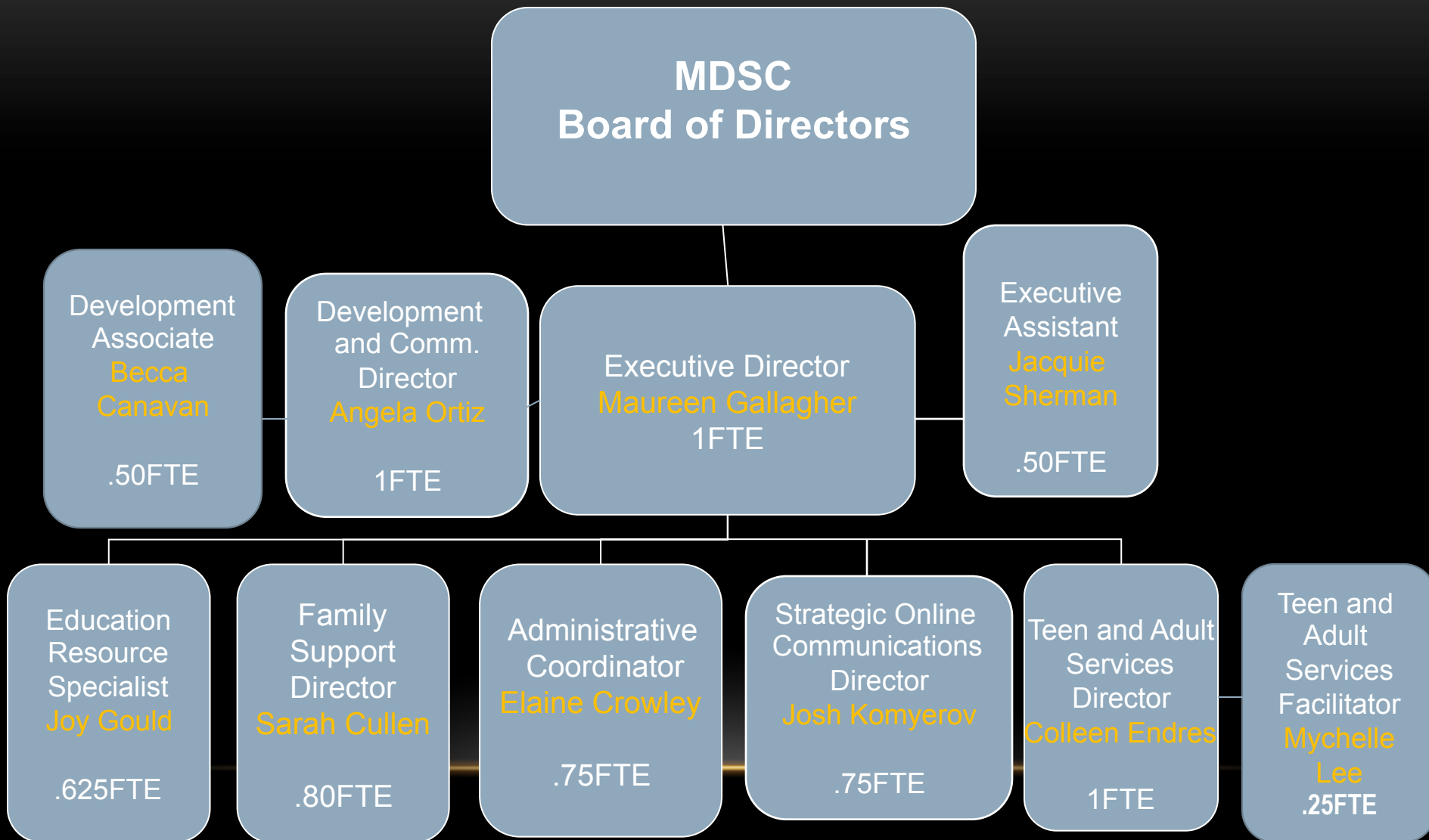


CAPACITY BUILDING

- MDSC management team increased to 7FTE's.
- MDSC Task Forces provided significant support to the organization. (Education Task Force, Public Awareness Task Force, Buddy Walk Task Force, Legislative Advocacy Task Force)
- More than 400 volunteers and interns provided hundreds of hours of service to support our programs.
- **THANK YOU TO OUR MANY VOLUNTEERS!**



ORGANIZATION CHART

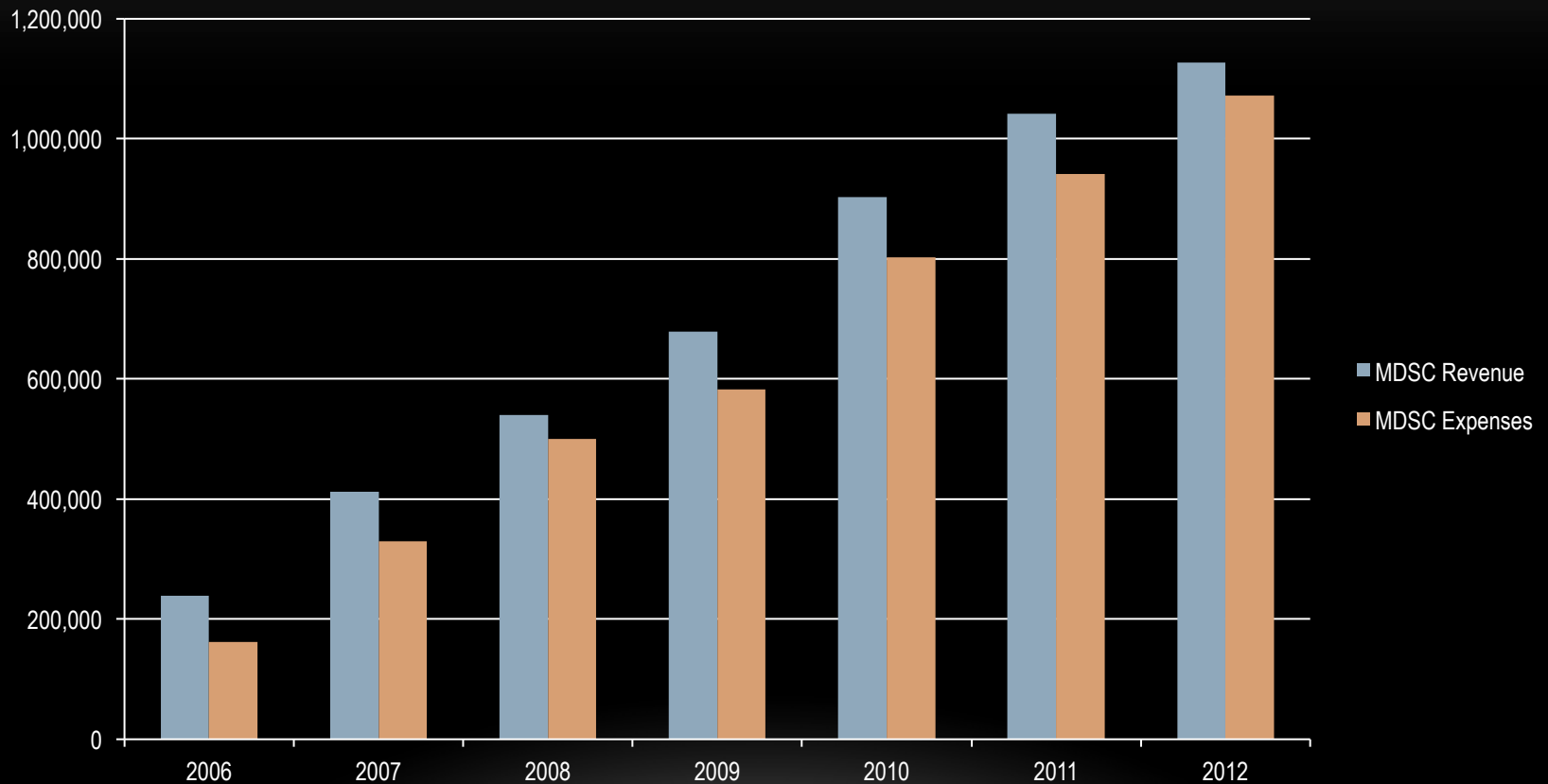


Financial Status



MDSC REVENUE AND EXPENSES

FY06 TO FY12



Strategic Direction



MDSC Strategic Plan

- Our Strategic Plan creates a road map for the MDSC through 2015
- Vision, Mission Statement, and Purposes

Strategic Plan: 2010-2015

1. To review, identify, evaluate, and prioritize the MDSC Purposes so that they meet the needs of the community
2. To continue to strengthen the capability and capacity of the MDSC Board of Directors and management team so that the MDSC's Purposes can be achieved
3. To ensure financial sustainability by strengthening and diversifying revenue sources so that the MDSC's Purposes can be achieved
4. To consider strategic alliances, associations, and other collaborative relationships so that the MDSC can better serve our communities by leveraging resources

Strategic Plan: Vision Statement

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.

Strategic Plan: 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.

Strategic Plan: New MDSC Purposes

1. To ensure that expectant families in Massachusetts receive accurate and up-to-date information about Down syndrome and desired supports.
 2. To better educate the public in Massachusetts about Down syndrome.
 3. To enable networking and direct supports for all people with Down syndrome and their families in Massachusetts.
 4. To educate our stakeholders through a clearinghouse of information about resources and advocacy, and transition planning related to Down syndrome in Massachusetts.
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STRATEGIC PLAN: NEW MDSC PURPOSES (CONT.)

5. To advocate for improved systemic change in issues such as community inclusion, transition, and employment for people with Down syndrome.
 6. To empower all people with Down syndrome to become effective self-advocates.
 7. To advocate that all individuals with Down syndrome in Massachusetts have high quality education, which includes transition planning.
 8. To advocate for all individuals with Down syndrome to have access to high quality medical services and research.
-

Questions and Answers



GOVERNANCE COMMITTEE REPORT

**MDSC
Governance
Committee Chair**

Ann Bersani

RENEWING BOARD MEMBERS

Anne Brensley

Michael Gunter

NEW BOARD MEMBERS

Election of New Board Members

Christopher Barnes
Kimberly Dever, M.D.
Jim Molla
Anne-Lise Wang

RETIRING BOARD MEMBERS

Special Thanks

Dave Kelleher

Jim Watts

Paul Karrlsson-Willis

Closing Remarks

Louise Borke, Board Chair