

MASSACHUSETTS DOWN SYNDROME CONGRESS

Information for Researchers

Organizational Overview

The Massachusetts Down Syndrome Congress (MDSC) is a statewide, non-profit organization that provides educational programs, direct support, publications, information and referrals, and individualized services to people with Down syndrome and their families, educators, health care professionals, and the wider community. The organization also supports legislation and public policies that improve the lives of people with Down syndrome.

MDSC has over 3,000 members, an energetic Board of Directors, and a dynamic management team. In 2009, Dads Appreciating Down Syndrome (D.A.D.S.) (which serves more than 250 fathers of children with Down syndrome) became an MDSC affiliate, and in 2011, the Down Syndrome Autism Connection (with close to 60 families) joined as an affiliate. MDSC maintains active partnerships with more than 20 like-minded organizations, institutions, and researchers and has been supporting research projects for over ten years. In spring 2012, MDSC's Medical and Scientific Advisory Council was established to increase the membership's access to medical and scientific information and resources and to facilitate partnerships between Down syndrome researchers, MDSC, and our members.

MDSC's mission is to ensure that 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. The organization's programs include:

- **First Call** works in partnership with hospitals throughout Massachusetts to provide education, one-to-one support, and playgroups to new families after their child is born as well as to parents whose children have been diagnosed during prenatal testing. Organizations from across the United States are turning to MDSC for guidance on starting their own First Call program; last year, MDSC provided technical support on First Call to organizations in Michigan, North Dakota, Louisiana, and Connecticut.
- **Family Connections** includes monthly social events and support group meetings for individuals with Down syndrome and their families. Support groups provide year-round opportunities for families to share new information, ideas and advice and increase their knowledge, understanding and hope about Down syndrome.
- **Advocates in Motion (AIM)** provides teens and young adults, ages 13-22, with and without Down syndrome with opportunities to form relationships and develop social skills; explore employment and community service opportunities; and gain greater control over all aspects of their lives.
- **Self-Advocate Advisory Council** is comprised of young people with Down syndrome, 21 years of age or older. The Council advises the MDSC Management Team on issues of importance to young adults with Down syndrome, the AIM program, and the role of the self-advocate. In addition to influencing the development and delivery of programs for young adults, Council members also develop leadership and self-advocacy skills.
- **Annual Educators Forum** is a day-long conference that provides 275 educators with information, resources, teaching strategies and best practices when working with children with Down syndrome in educational settings.
- **Annual Conference** is attended by more than 600 people each year, including parents and other family members of children with Down syndrome, therapists, educators, health care professionals,

researchers, and teens and adults with Down syndrome. Includes networking opportunities and workshops on self-care, self-advocacy, transition to adulthood, health issues, and cutting edge developments in the field.

Recent Research Projects

For over 10 years now, MDSC has supported researchers by informing members about opportunities to participate in research; facilitating communication between members and researchers; serving on research design and implementation committees; linking researchers to regional and national experts in the field; and assisting with dissemination of findings/reports. Examples of recent studies that MDSC has supported include:

- **Employment/Unemployment/Jobs Survey for People with Down Syndrome.** Conducted by Dr. Libby Kumin of Loyola University Department of Speech-Language Pathology/Audiology, this study consists of an online survey to gather information on the current employment and unemployment status for adults with Down syndrome, ages 18-50 years old.
- **Smooth Sailing Research Study for Children with Autism.** Conducted by Abbey Eisenhower, Ph.D., Assistant Professor in the Department of Psychology and Clinical Psychology Ph.D. Program at UMass Boston, the Smooth Sailing Study, funded by the Institute of Education Sciences, is aimed at understanding the transition to school for children with autism spectrum disorders (ASD) or children who are dually diagnosed, such as children with Down syndrome and autism.
- **Team Up For Fitness (TUFF).** A Community Based Exercise Program for Adolescents with Down Syndrome, TUFF is a research study funded by the National Institutes of Health. It is being conducted by faculty at the UMass Medical School's Eunice Shriver Center. The TUFF study is a 12-week exercise program followed by a 12-week supported maintenance period for healthy adolescents with Down syndrome ages 13-21.

How MDSC Supports Research Projects

MDSC's Medical and Scientific Advisory Council works directly with researchers and scientists to determine what research studies to support and how the MDSC can best support the project goals. Each research proposal received is carefully reviewed for content, ethics, and feasibility, as well as potential benefits to the community and impact on participants. MDSC is sensitive to the confidential nature of our membership information, and, at no time, does the MDSC sell or share member information with researchers. Research proposals must include the full study and IRB approval. If approved, MDSC can offer a variety of supports to researchers, including;

1. **Recruit participants for research projects:** MDSC informs its members about research studies through direct e-mail, mail, and phone contact; the MDSC website; and announcements at support groups, conferences, and educational events. MDSC will also facilitate communication between members and researchers throughout the project.
2. **Serve on IRB Committees:** Depending on the needs and focus of each committee, MDSC staff, members of the Medical and Scientific Advisory Council, family members of people with Down syndrome, and/or MDSC self-advocates (young people with Down syndrome, 21 years of age or older) can provide an important voice on research committees. Committee involvement may be ongoing through the duration of a project or focused on a specific component of the research or dissemination. For example, a staff person or family member may be helpful in clarifying obstacles that may arise when working with families; a self-advocate may provide information about what

incentives might be appropriate when engaging young people; and a member of the Advisory Council might provide critical insights about the research goals.

3. **Connecting researchers to regional and national experts in the field:** MDSC's Medical and Scientific Advisory Council (see biographies, attached) is comprised of some of the foremost regional and national experts in Down syndrome. In addition to these individuals, MDSC has connections to professionals across the country with expertise in Down syndrome and other physical, cognitive, and behavioral disabilities.

4. **Dissemination of findings/reports:** Not only can MDSC assist in disseminating results directly to its 3,000 members (including 275 educators, hospitals across Massachusetts, and funders), we also have connections through our listserv that includes more than 30,000 family members and supporters. We also have direct links to more than 500 social service providers, government agencies, schools/colleges, and health care providers around the country. MDSC disseminates information via our website, through local coalitions, educational events, statewide and national conferences, and the media.

Cost Estimate

The following cost estimates for each type of research support activity provided by MDSC are not binding – they are intended only to provide a general idea of related costs. Final costs will be developed in cooperation with each researcher to reflect quantity and duration of actual services to be provided by MDSC.

Type of Service	Annual Cost Estimate (for projects 1 year or more in duration)
<p>1. Recruit participants for research project. MDSC Research coordinator to leverage MDSC relationships with families, self-advocates, and other disability organizations to yield high results for recruiting participants for the study. This is an ongoing intensive personalized recruitment campaign that will include making phone calls and following up with potential study participants. (approximately 2 hours/week for 52 weeks including materials and supplies to support outreach/follow-up efforts)</p>	<p>\$12,600</p>
<p>2. Serve on IRB Committee. MDSC staff person or designated family member or self-advocate serves in an advisory role for the project.</p>	<p>Reimbursement of travel related costs and stipends for family members or self-advocates recommended</p>
<p>3. Dissemination of findings/reports: Estimated at 10 hours of dissemination activities to include MDSC webpage, MDSC newsletter, and MDSC e-newsletter for a combined outreach to 30,000 individuals and organizations throughout the United States with higher concentration in the Northeast.</p>	<p>\$500</p>
<p>4. One time research recruitment campaign:</p> <p>a. Electronic outreach campaign consisting of posting on the MDSC webpage, article in the MDSC e-newsletter, separate e-blast about research project to 30,000 individuals and organizations throughout the United States. - \$500 (note: for repeat outreach campaigns, subsequent cost is \$250)</p> <p>b. Targeted outreach mailing to individual family members or self-advocates on the MDSC database - \$500 plus the cost of postage and materials.</p>	<p>\$500 for first electronic campaign and \$250 for additional campaigns</p> <p>\$500 for outreach mailing plus cost of postage and materials</p>
<p>5. General consultation to research project: MDSC staff person serves as consultant to the project providing feedback on research design and implementation.</p>	<p>\$50/hour</p>