



SOMETHING EXTRA

The Newsletter of the Miami Valley Down Syndrome Association
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Proud Supporters of:



MVDSA's 3rd Annual, 2005 Buddy Walk

Much to our dismay, the summer is rapidly disappearing, school is again here, and the summer heat wave we awaited all winter long is dissipating entirely too quickly... all of this to break the news to you... October 1st is less than a month away! That's Right! Our 2005 Buddy Walk is HERE!

After the incredible success of the MVDSA's 2004 BUDDY WALK, we have increased our goal from

last year and want to raise \$30,000 this year. Unsure of the exact amount, we are sure we had more than 500 walkers last year and are hoping to have at least 750 walkers to participate in promoting the acceptance and inclusion of individuals with Down syndrome. This is a great opportunity for all of us involved with the MVDSA. Along with NDSS, this is a nationally recognized walk that gives us the opportunity to promote acceptance, inclusion, advocacy, and research for all of those with Down syndrome. If you haven't already registered... do it now! Join us for a day of great family fun, food, entertainment, and celebration of those we love affected by Down syndrome. We will also be displaying a "Wall of Achievement" in honor of the MVDSA's individuals with Down syndrome. Please call the MVDSA office for registration forms, Team information packets, to include an individual in our "Wall of Achievement", or any additional questions regarding the event. Be a part of our nationally recognized BUDDY WALK, join us on Saturday, October 1, 2005, registration begins at 9am.

Amber Thomas, Chairman

Note: Please see Mary Fischer's recent letter (mailed separately) for details on the "Wall of Achievement" and the Talent Show"

The Buddy Walk was started by the National Down Syndrome Society in New York City and has grown from 17 walks around the country in 1995 to more than 190 walks in 48 states in 2003. The goal of the Buddy Walk is to promote understanding and acceptance of people with Down syndrome.

5th Annual Ohio Adult Sibling Conference—October 7 & 8, 2005
Columbus Airport Marriot Hotel

Register today for this exciting conference and see for yourself what all the "Talk" is about! Conference fee is \$80 and includes meals and materials. For more information contact Tom Fish, Ohio State University Nisonger Center, (614)-202-7550 or e-mail: fish.1@osu.edu. Financial assistance may be available through your local County Board of MR/DD. Contact MVDSA office for agenda details. (937) 222-0744.



MVDSA Annual Summer Picnic

The wonderful odor of hamburgers grilling, the sounds of children laughing and friends greeting each other, country music, and a wonderfully gentle breeze which helped cool things off describe the annual MVDSA Summer Picnic held this past Saturday afternoon at Indian Riffle Park.



A good time was had as everyone ate, played and talked with old friends. We had some new members there, and it was great to see them. The bean bag and milk bottle games were popular with the younger set, as well as the beads and sand art, while the teens and adults, assisted by Barb Schramm, enjoyed the tee-shirt tie-dyeing. Justin Sayger treated us by agreeing to sing a couple of songs, which were enjoyed by all. We also had croquet and badminton set up, but before anyone had a chance to play, our cooling breeze turned into a gusty thunderstorm, and most everyone dashed for their cars before the storm hit.



Although the picnic was short, it was sweet - many thanks to all who helped and all who participated. We had a great time, and are already looking forward to next year's picnic.



Info on the Web

The following information was sent in by member Paige Vagedes.

"I take Julian to therapy at Children's Medical Center and his speech therapist gave me this website that is great! I thought you could check it out and possibly find some things that would interest other parents/caregivers. The website is www.talktoolstm.com . Please look under oral motor articles at the top of the page (and wherever else you like too), they have great information on Down syndrome children etc.."

From the Office . . .

Summer is over. For those of us with school-age children, or for those who work in the education industry, summer's ending signals a return to a stricter schedule. It's always a little sad for me to see the end of summer but at the same time, it's a time of new beginnings—sharpened pencils, new books and crayons, renewal of friendships and renewed resolve to make this the best year yet.

Our daughter is entering 3rd grade this year; our middle son is in 7th and our oldest son will be starting on his Master's Degree! Each of them is starting out a new school year with their special abilities - *and* their disabilities. I've heard our President, Mary Fischer, talk about focusing on our Down syndrome children's abilities rather than their disabilities. That's a meaningful statement with a positive outlook. It is just as meaningful though in regard to each of us. As parents/caregivers of Down syndrome individuals, we are sometimes prone to *feel* disabled when it comes to knowing just how to be the caregiver, advocate, teacher, or support that we feel we need to be. Sometimes, even our "want-to" is lacking. The Miami Valley Down Syndrome Association exists to support us in both of those areas. We all have our strengths and weaknesses, our times of being "on top of things" and our times of discouragement. Doesn't it make sense to join together and support one another so that we can be more consistent in our efforts? We each have unique contributions that together can make a difference. When we get involved, we all benefit. It doesn't matter so much that your part is large or small; it matters that you take part. Starting point: if you're not a member, become one (or renew)! If you can be a faithful once-a-quarter meeting attendee, we need you for that. You may be the one with an answer or listening ear for that new parent. If you can volunteer to be on one of our committees – wonderful! If you can help set up before or take down after a meeting - very much appreciated. Come and help us fold and stamp newsletters or envelopes. Take part in the Euchre Tournament or the Buddy Walk. Select an opportunity and Come join us! *Cathy Shane*

Think of Fall 2005 as your new beginning with MVDSA!!



"3rd annual Buddy Walk"

**Saturday, October 1
Delco Park—Kettering**

Be a part of our nationally recognized BUDDY WALK, join us on Saturday, October 1, 2005, registration begins at 9 a.m.

See page 1 for details

Lexis Nexis Hand-in-Hand festival*

September 10, 2005 10:00 a.m. – 2:00 p.m.

63 people have signed up to participate

*** LexisNexis campus, 9333 Springboro Pike**



September meeting—Thursday, September 15th

Dinner—6:30 p.m. Guest speaker 7 p.m.

Indiana Dad's support group guest speaker

Babysitting / childcare provided. See page 6 for details.

October meeting—Thursday, October 20th

Glen Evans—Professional Speaker & Trainer

Dinner—6:30 p.m. Guest speaker 7 p.m.

Babysitting / childcare provided. See page 4 for details.

Fall Fest / Dance

Saturday, October 15th @ 5:30 p.m.

See page 7 for details



Advocacy Research and Education

www.ndscenter.org

800-232-6372 *The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down syndrome.*

www.thearcofohio.org

800-875-2723 *The mission of The Arc of Ohio is to advocate for human rights, personal dignity and community participation of individuals with mental retardation and other developmental disabilities, through legislative and social action, information and education, local chapter support and family involvement.*

www.wrightslaw.com

Parents, advocates, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities. You will find articles, cases, newsletters, and resources about dozens of topics in the [Advocacy Libraries](#) and [Law Libraries](#).

www.downsed.org

The Down Syndrome Educational Trust exists to make a positive difference for individuals with Down syndrome worldwide by conducting original scientific research with practical outcomes, disseminating current and accurate information and advice, and by providing independent, specialist consultancy and educational services.

www.ndss.org

The mission of the National Down Syndrome Society is to benefit people with Down syndrome and their families through national leadership in [education](#), [research](#) and [advocacy](#).

Down Syndrome: Health Issues

News and Information for Parents and Professionals

by Len Leshin, M.D., F.A.A.P.

Author's note: I'm a pediatrician and the father of Avi, 11 years old, and Nathan, 13 years old. [\(Photos!\)](#) Avi has Down Syndrome ("DS" for short) and has inspired me to write these essays about

children with DS for other parents. I have put them here for general reading. You may [E-mail me](#) with any questions about these essays. I have also included some other pediatric items of interest for parents.

[More up-to-date photos of Avi here!](#) June 2005: *A new photo!*

Been here before? Check out [what's new!](#)

For students writing reports, I have put together [this page on Down syndrome](#) to help you.

<http://www.ds-health.com/>

A useful website to check out, used by permission

Thursday, October 20, 2005 General Meeting — Job Center @ 1133 S Edwin C Moses Blvd

Dinner at 6:30, business meeting 7 Speaker at 7 p.m. (baby sitting provided)

Glen Evans—Professional Speaker AND Trainer on personal Safety

Of 'RAD Systems for Women', 'RAD Systems for Kids', 'Personal Safety Workshops'

Glen will be talking with us about personal safety and promoting the November 5, 2005 self-defense class we are offering to our members with Down syndrome. Both parents of children with Down syndrome and our Teen/Adults with Down syndrome will benefit from Officer Evans presentation and everyone will certainly learn from this great opportunity. Safety is an issue that we tend to overlook, but if you watch the evening news, safety is something we should all be thinking about. The MVDSA has also booked Glen Evans for a workshop to provide our individuals with Down syndrome some practical hands-on experience at personal safety. The class is designed for typical children at a mature five year old development level. We are suggesting that each individual with Down syndrome bring a parent or adult sibling along to help them at this workshop. The workshop will cost \$5 per registrant; the MVDSA will pay for the majority of the cost. A consent/information form will be needed, please call the MVDSA office for forms and to reserve your spot.

To reserve a spot in the November 5, 2005 self-defense class, we must have your reservation by Thursday, November 3, 2005. These are two opportunities we hope that EVERYONE will take advantage of!

A letter from NDSS regarding the Hurricane Katrina disaster...

This is a way we can specifically help affected DS individuals and their families.

September 1, 2005

Dear Friends:

Like all of you, we have been terribly saddened and distressed to see the devastation caused by Hurricane Katrina in Alabama, Louisiana and Mississippi. We share your deep concerns for the many people affected by this tragedy, including individuals with Down syndrome and their families in these areas.

We have heard from Karen Scallan from the Down Syndrome Association of Greater New Orleans, who reports that many of their members have lost their homes and are now in Texas, Tennessee, Florida and other locations. She is working to track down people they have not spoken to yet. Karen thanks everyone for their prayers and thoughts!

Laura Sherman from the Mobile Area Down Syndrome Support Group is also working to reach out to members in their area who have been displaced by the hurricane, and also expresses her appreciation for everyone's concern.

We have reached out to Kim Duffy at the Gulf Coast Down Syndrome Society, but have not heard back from her yet.

The National Down Syndrome Society (NDSS) has established the *Katrina Fund for the Down Syndrome Community*, which will be a temporary fund to raise money for the Down Syndrome Association of Greater New Orleans, the Gulf Coast Down Syndrome Society and the Mobile Area Down Syndrome Support Group.

NDSS has made an initial contribution of \$3,000 to the fund, and we invite other interested individuals and groups to donate to the fund either online [HERE](https://secure.ndss.org/content.cfm?fuseaction=Support.Donate) (<https://secure.ndss.org/content.cfm?fuseaction=Support.Donate>) or by mailing a check to NDSS at 666 Broadway, 8th Floor, New York, NY 10012. All checks should include "Katrina Fund" on the memo line. **The deadline to contribute to the fund is September 30.**

All monies (100%) collected through the fund will be distributed in October directly to the affiliate groups in Gulfport, New Orleans and Mobile to support local people with Down syndrome and their families. Each affiliate group can decide how to best utilize the funds by giving cash donations to families in need, buying books for children, supporting their local group activities since their Buddy Walks might not take place this year, or anything else that will be the most helpful!

We realize that even our most generous contributions will be small in relation to the needs but they will be large with respect to the heart of our community. Whatever the amount, the funds will be distributed in an equitable fashion to the three groups, deferring to their best judgment about how best to use these funds in their respective Down syndrome communities.

If you or your group is interested in contributing in other ways (e.g. offering housing for displaced families, sending supplies, etc.), we suggest contacting the affected groups directly. Any offers of assistance for New Orleans can be directed to Karen Scallan (kscallan@cox.net), copying Mike Rapier (DSAGNO@aol.com). We will post updated information about the other groups on www.NDSS.org as it is available.

Thank you in advance for opening your hearts to the many members of our Down syndrome family who are facing unbelievable hardships as a result of Hurricane Katrina.

Sincerely,

Pam van der Lee
Chair, NDSS Board of Directors

Alan P. Brownstein
President, NDSS

Commonplace minds usually condemn what is beyond the reach of their understanding.

Francois de La Rochefoucauld

Criticism is something we can avoid easily

-by saying nothing, doing nothing,

And being nothing.

Artistotle

Website update

Coming a little later in the future will be the revised and much improved MVDSA website. The changes have been under construction but with a volunteer staff, development work is not always fast in coming. The current MVDSA logo has been with us a good many years and we have some revisions under consideration for that also. As with our kids, young people, and adults, we look to our/their future. We want to get better at finding and presenting information to our DS families and community. As the changes are made, they will be posted to the website and in the newsletter.

The Editor

In Memory of Randy L. Mathes

DOB: 02/16/59 DOD: 07/04/05

Our condolences go out to the family and friends of Randy Mathes. The following biographical information was supplied by Lee McCormick, Randy's sister.

Randy may have been one of the first Down Syndrome children in the area to be involved in some structured play/education/work programs. When Randy was as young as 5, my mom and her friend, Anne Bertorello, took their sons to a play group in an old church on Brown Street near the Oregon District. This was, to the best of my knowledge, the first place that was home for the MR/DD program. My guess is that it was more of a support group for the parents than anything else, but it was a good thing for them both, even though Mom had to take the bus to get there.

Randy attended various MR school programs, at Christ United Methodist Church in Kettering, and then eventually at Southview School on Thorpe Dr, where he was a member of the basketball team. Randy graduated from Southview School in 1982. From there he went to work at the Monco Sheltered Workshops, and moved into the QRA Group Home on Glen Martin drive around 1986. Mom and Dad were always very active in the Council for Retarded and various Down Syndrome groups over the years, as well as the parent support organization at the Monco workshops. They were very active in the Knights of Columbus #3730. Randy attended many events with them, and was considered part of the "family" at K of C events.

Randy's great loves were UD Flyer basketball, the Cincinnati Reds, the Dukes of Hazzard, and Elvis. Randy will be best remembered for his friendly smile and unconditional love.

Randy is survived by his mother, Sally Mathes; siblings, Denis (Sue) Mathes, Sally (Gary) Smieszny, and Lee (Gene) McCormick; six nieces and nephews; and his lifelong friend, Tom Bertorello.

In a note to the office, Lee wrote, "Randy was my brother but more importantly, a sweet and loving person. . . Our family is glad that your organization is able to help other families in his memory and honor." To that end, donations were made and received by MVDSA in memory of Randy and the donors are listed below.

Donations were made to memory of Randy Mathes by the following: Irene Turckes Doris Gast Kimberly & Robert Slack Tony Bornhorst & Dina Arias-Bornhorst	Carl & Deloris Elam	Anthony & Janis Winner
	Robert & Debora Less	Jeff & Jacqueline Brumfield
	Patricia & Hugh Smith	Donald & Arlene Deis
	Lynn Menard	Mark & Teresa Poeppelman
	Karen & David Williams	Donald & Betty Lett
	Kenneth & Linda Hurt	Joseph & Deborah Richey
	Kristina Flick	George & Barbara McCormick

Other monetary donations: United Way of Greater Dayton

Non-monetary donations: Brian & Cindy Wilson (*large* box of "Barrels of Monkeys")

Thursday, September 15, 2005 General Meeting

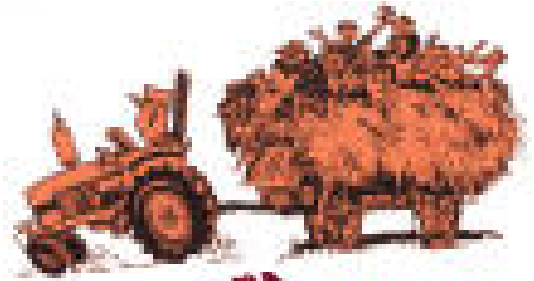
Job Center @ 1133 S Edwin C Moses Blvd

Dinner at 6:30, business meeting 7 Speaker at 7 p.m. (baby sitting provided)

We will be listening to a member from an Indiana Dad's Support Group tell us how they began their group to promote activities for Dads and their Down syndrome children. We assume that some of the time this might function as a support group and Dad's Night Out also?! At any rate, it seems to have met with success and acceptance in their Down syndrome association and we're eager to *check it out*.

Come for a fun time at the Bridenbaugh's Farm. They have a huge barn that they have graciously donated for our function. Come Saturday, October 15th, starting at 5:30 p.m. Bring a covered dish—meat and drinks will be provided. There will be a hayride, weather permitting.

Young people (maybe even some adults) bring your dancing shoes. The details have yet to be worked out, but we hope to have a dance that evening. Call the office for details (937) 222-0744



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Maps

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Happy Birthday!

Raymond Coles	9-2
Michael Fischer	9-3
Jennifer Cowden	9-4
Steven Barker	9-15
Arte Komorowski	9-20
Maria Fox	9-28



Krista Raggio	10-4
Carlee Rae Hayes	10-9
Jon Larson	10-13
Doug Hoyer	10-16
Will Day	10-16
Kylie Hannan	10-18
Alex Short	10-27



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General Meeting

Thursday — September 15, 2005

6:30 p.m. dinner

7:00 p.m. meeting and

Guest speaker from the Indiana DAD's support group

MVDSA Fall Fest & Dance

Saturday, October 15th 5:30 pm



General Meeting

Thursday — October 20, 2005

6:30 p.m. dinner

7:00 p.m. meeting and

Personal Safety Guest speaker-Glen Evans

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Policy Statement: The MVDSA does not endorse, recommend, or support any particular regime, therapy, or treatment.

Printing of Articles:

We welcome articles from parents, professionals, and other interested parties. Material for consideration must be submitted to the MVDSA, 1133 S. Edwin C. Moses Blvd, Suite 190, Dayton Ohio 45408-2071, or send to Editor@mvdsa.org.

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