



SOMETHING EXTRA

The Newsletter of the
Miami Valley Down
Syndrome Association
www.mvdsa.org

Volume 28, Issue
May - June 2005

Lesson #1 for new parents: 'Make time for you'

Make time for you – even if it's just a few minutes each day. Read a magazine article, take a hot shower, have a cup of coffee. Do what you want to do for those few minutes and do not feel guilty about it.

You do not have to jump up every time the phone rings. Use your answering machine to pick up calls. If it's important, they will either leave a message or call you back. Don't be afraid to turn your phone ringer to the "off" position, either.

Walk a few laps around your house. Better yet, put baby in the stroller and go for a lap or two around the block.

Reach out to other parents in other groups such as Help Me Grow or MVDSA or your church. Talk to other new moms and dads about how you're feeling. They may be

feeling the same way. In the case of your Down syndrome child, talk to other parents at our monthly meetings; chances are they have "been there" or know someone who has. Make time for the relationships you have that extend beyond parenthood. Make a date with your spouse even if that means cold Chinese food at the coffee table at 9 p.m.

Sleep when your baby sleeps. Really. You need to rest too.



Accept help from others. If someone offers to make you dinner or to play with the baby for a few hours so you can nap, say "yes". You do not wear tights, a cape and a giant "S" across your chest.

You do not have to take the advice of every veteran parent out there,

including your own parents and in-laws. It seems that everyone has an opinion on parenting but only you will know what is best for your family and for our baby.

If you feel overwhelmed by parenthood, call your family support specialist or your service coordinator to discuss your feelings and what you can do to feel more at ease with your new role.

Become informed and involved with your county Early Intervention Center and the Down syndrome Association. Take advantage of what these groups and your county has to offer. Attend support groups, playgroups, and collaborative meetings when you have time. You are a very important person in the program and will be appreciated for your participation.

Spotlight Night*

*An evening to feature our Down syndrome members

- **Dinner from 6:30 – 7:00 p.m.**
- **Short business meeting**
- **Officer elections**
- **Spotlight on Talent**
- **Scholarship distribution**

There is still time to participate in the talent portion of the evening. Call the MVDSA office (937-222-0744) with the following information: participant's name and age, parents' name, and talent to be featured by May 17. We also need

Thursday, May 19, 2005
At the Job Center Cafeteria



to know whether you will need to use a tape or CD player. (We'll provide those). Otherwise bring your still and/or video camera and enjoy!

Note: Each participants will be given 3-4 minutes of performance time.

You won't want to miss this evening!

Library News:

New!! Love and Learning Kits # 1—7

These are available for parents to check out (literally). Take the tapes and booklets home; try them out without the big up-front expense.

Inspirational Books

For new parents: Sometimes Miracles Hide- Stirring letters from those who discovered God's blessings in a special child.

Choosing Naia is the story of Greg and Tierney Fairchild learning that they were expecting a child with a heart defect and Down syndrome,

their decision to continue the pregnancy and the gift they received in their daughter, Naia.

For parents of children of all ages, Don't Sing any Sad Songs is the story of the journey of one Down syndrome young woman "who moved away from home as a young adult, and lives a loving, joy-filled, productive life."

You Will Dream New Dreams is a book of essays written by veteran parents who share their stories and wisdom gained from raising their Down syndrome child.

In the Hospital

Becky Shonle is in the Intensive Care Unit at Miami Valley Hospital in serious condition. Becky has been the Playgroup chairman and Board member this past year. She and husband John are parents of John, Becky and Anna (DS). You may call the office to get updated info on her status. (Amber Thomas forwards e-mail updates that she gets from John.) A member of their church is coordinating meals and would appreciate MVDSA members' help; Call Sally at 256-2263 if you would like to volunteer.

IDEA reauthorization

When IDEA was reauthorized in 2004, it included several critical changes that will affect the law as it exists today. Many of these changes go into effect July 1, 2005. A summary of some of the significant changes to IDEA is available at the National Parent Centers Web site, www.nationalparentcenters.org. Click on the "IDEA 2004 summary" link.

Mark your calendar

May 20-21, 2005 (May 12 registration deadline)

International Research and Parent Conference on Down Syndrome

To be held at Northern Kentucky Convention Center, Covington, Kentucky. There will be a professional track on Friday and a parent track on Saturday to address a broad variety of topics.

Parents, Family and Guardians Fees:

\$80 - one person, one day only

\$150 - one person, two days

\$150 - two people, one day only - Fri OR Sat

\$275 - two people, two days - Fri and Sat

We have registration forms in the MVDSA office if you are interested; since the registration deadline is May 12, you will want to fax this form to 513-381-0401. Register online at <https://programs.regweb.com/mit/cchmc/welcome> or call 888-265-3565. Checks are to be made payable to **The Thomas Center**.

June 5, 2005 (tentative date/location)

MVDSA Strategic Planning Meeting

This to be held at Becci and Pat Willoughby's house. Our second meeting in an ongoing process, we will meet to assess our progress, fine tune our goals, and "flesh out" our 2005-2006 calendar with monthly meeting plans and extra activities. This planning forum is open to all interested voting members. Call the office for the latest details ahead of the meeting date.

June 16, 2005

Monthly Business Meeting- details later

July 7-10, 2005 (June 13 registration deadline)

NDSS National Conference

Hosted by the NDSS and the National Association for Down Syndrome (NADS). At Fairmont Hotel, Chicago, IL. The conference will include an affiliate day, a self advocate track, and general programming for all who are interested in or affected by Down syndrome. There are four ways to register: Submit online at www.ndss.org, Fax to (973) 828-0442, call (800) 799-4113 and mail to: NDSS Conference Registration, 506A Main St., Boonton, NJ 07005

July 29-31, 2005

NDSC National Conference

The 2005 NDSC National Convention is scheduled at the Hyatt Regency Orange County in Anaheim, CA.

July 31, 2005

Deadline for MVDSA membership renewal. Mail completed forms to the office address listed on the back of this newsletter.

August 20, 2005

MVDSA Picnic

Indian Ripple Park 1 - 5 p.m.

September 10, 2005

Lexis-Nexis Hand-in-Hand Festival

10 - 2 p.m.

October 1, 2005

Buddy Walk - Delco Park

OHIO DD COUNCIL SEEKS INPUT

The Ohio Developmental Disabilities Council wants to know what you think are the most important issues facing individuals with developmental disabilities and their families. We are preparing the next Five Year State Plan for Developmental Disabilities, which is due to the Administration on Developmental Disabilities in August, 2006.

Forums - Council members and staff will listen to people with Developmental disabilities, parents and other family members, and advocates. Comments will be recorded and shared with all Council members. Please register to speak when you arrive.

DAYTON

Wednesday, June 15th Kettering Family Education Center
10:00 a.m. to

Noon Carillon Historical Park
1000 Carillon Blvd.
Contact at the Park:
Shawn 419-293-3841, ext. 106

Other dates available in Columbus, Cincinnati and Cleveland.

Call the MVDSA office at 937-222-0744 if info needed.

SURVEY - A brief survey is available online at www.ddc.ohio.gov, or by e-mailing Mary.Smithson@dmr.state.ohio.us or calling 614-466-5232 and leaving your name and address. Surveys should be returned by July 1st.



“Life Goes On” DVD Campaign

“Life Goes On” was a groundbreaking ABC television series featuring Chris Burke, NDSS goodwill ambassador, as Corky, the first character with Down syndrome on a network series. The family drama aired from 1989 to 1993 and dramatically increased public awareness of Down syndrome. Gail Williamson,

executive director of the Down Syndrome Association of Los Angeles, will be meeting with Warner Brothers Home Video in the near future to discuss the possibility of re-releasing the first season of “Life Goes On” on DVD. Gail has requested letters from self-advocates, parents, family members and friends to demonstrate that there is a huge demand for this DVD in the market. If you want to help make “Life Goes On” available to a new generation of viewers, please write a letter to Warner Brothers Home Video explaining why you would buy “Life Goes On” on DVD, and what the show means to you.

Send letters to: Gail Williamson, Down Syndrome Association of Los Angeles, 315 Arden Avenue, Suite 25, Glendale, CA 91203; email: gail@dsala.org; fax: 818-242-7819.

Editors Corner... First, I would like to thank the new office administrator, Cathy, for her tremendous help getting this newsletter together; In fact for pulling most of it together. We have a number of action items coming up and I hope that each of will get involved even if in some small way. Our goal is to make MVDSA an organization that provides support and encouragement for the entire group. We all have our challenges even if just with life itself. Having more people involved is such an encouragement to the rest of us. I hope to see even more involvement. We tried to feature some items that allow our DS members safer and hopefully easier participation in life.

Product Reviews

ID, Please

Who's Shoes ID Band, \$7.99

This handy ID kit is perfect for the parent who knows the sinking feeling of fear when your child can't be immediately found. The simple, Velcro band is worn on children's shoes and contains emergency information intended to help reunite parents and lost kids. Perfect for small children, youngsters challenged by disabilities and even joggers. Available at www.whosshoesid.com.

California Baby

If chamomile, mandarin and rosewater sound like something your baby could appreciate, check out this line of products – available in select stores and online – offers everything from aromatherapy for the “overtired and cranky” to essential oils for treating diaper rash. A vegetarian mom looking for holistic products created the line, which is free of sulfates, DEA, gluten, soy, dyes, synthetic fragrances or numbing agents. Available at www.californiababy.com

My, What wonderful children you have (just for fun!)

Available in gift stores nationwide, \$5.99 and up. Remember Mr. Wonderful, the man doll who said all the right things? We'd like to introduce you to his **Wonderful Kids**, including the exemplary son who says, “Can I have some more vegetables please?” and his perfect sister, who is just as likely to say, “I don't want to date until I'm at least 21.”

Fat Wheels

Check out these sturdy training wheels! The training wheels work well for older children with balance issues and fit bikes up to 26” in size. The “fat wheels” enable children with special needs to be successful bike riders. Price ranges from \$70—\$130. These may be purchased at K & G Bike Center, 4090 Marshall Rd, Kettering. Contact John Duerr at 937- 294-6895 for more information. K & G Bike Center can install if you choose.



Abilities First—Summertime Therapy—4710 Timber Trail Drive—June 6 – August 19, 2005

For more information call Bettie Rountree at 513-423-9496 or 800-378-8612

The Summertime Therapy program is open to children with special needs. All groups are designed and led by licensed therapy staff and encourage social interaction, cooperation and turn taking with peers, while providing therapy input specific to the needs of the children. **Individual outpatient therapy is also available.**

Terrific Toddlers

Provides play-based experiences for children ages 18 to 36 months who present with language and/or motor delays. These therapeutic experiences foster socialization, communication, motor skills and openness to sensory exploration.

When: Wednesdays & Fridays, 9:30-11:00am

Staff: Speech-Language, Occupational and Physical Therapy available

Therapeutic Preschool – (full; currently taking names on waiting list)

Therapy based preschool program for children ages 2 ½ to 5 years who show at least a 6-month speech-language and/or motor delay. A variety of life experiences, sensory exploration, communication opportunities and motor activities are utilized to prepare children for future classroom expectations.

When: Tuesdays & Thursdays, 9:00-11:00am or 12:00noon-2:00pm or 2:30-4:30pm

Staff: Speech-Language, Occupational and Physical Therapy available

School Readiness – (full; currently taking names on waiting list)

A therapeutic group for children ages 4 to 6 years who demonstrate difficulty with speech-language skills, cutting, writing and other basic concepts for academic success in Kindergarten and First grade. The group creates learning opportunities for children to develop classroom social skills and peer relationships.

When: Wednesdays & Fridays, 12:00noon-2:00pm or 2:30-4:30pm

Staff: Speech-Language, Occupational and Physical Therapy available

Feeding Group

An 8 week caregiver/child group for children ages 3-7 years with eating challenges. This group will provide opportunities to build a support network with other parents and create a positive eating experience. We will be exploring a variety of sensory experiences, determining appropriate positioning options and increasing the child's oral strength and coordination. Caregivers will remain with the child and participate in the group activities.

When: Mondays, 3:00-4:00pm

Staff: Speech-Language and Occupational Therapy available

Write Right

A group offered to school age children who struggle with simple pencil-and-paper tasks and/or demonstrate poor legibility. Therapists introduce a variety of activities to improve fine motor coordination, eye-hand coordination, hand strength and sensory awareness. In addition, a variety of modifications and techniques are introduced to boost handwriting skills.

When: Mondays, 10:30am-12:00noon

Staff: Occupational Therapy available

Abilities First—Summertime Therapy (continued)

Community Outing Group

A group that provides school aged children with a variety of therapeutic experiences in recreational, social and community settings that improve their social interactions, self-esteem, functional mobility, self-help and cognitive skills through their active participation. Therapy staff and volunteers will safely supervise all outings. Transportation for the outings is provided by our specially equipped van.

When: Wednesdays, 12:00noon-4:00pm

Staff: Physical, Occupational and Speech-Language Therapy available

Independent U.

A group open to ages 9 years and up that will provide therapeutic opportunities to practice basic activities of daily living and to develop and improve safety awareness. The kids will interact in both "home-like" and community settings. Activities will be designed to encourage age appropriate language and learning opportunities while developing the more independent YOU.

When: Tuesdays, 12:00noon–2:00pm

Staff: Occupational and Speech-Language Therapy available

Summer Survivors

Fun and Fitness for children ages 8-16 years who currently experience motor difficulties such as poor balance, muscle weakness and low endurance. The children will be provided with opportunities to explore unique activities on site and in the community. Participants will be introduced to challenging and stimulating experiences to encourage healthy lifestyle changes. Therapy staff and volunteers will safely supervise all outings with transportation for the outings provided by Abilities First van. Participants must walk independently and be able to consistently follow simple directions.

When: Thursday, 12:00noon-4:00pm

Staff: Physical Therapy available

Fun Factor I

A sensorimotor group for children ages 2-4½ years who demonstrate difficulty with sensory modulation/regulation, motor planning and body awareness. This will be an exploratory group providing children with opportunities to participate in and explore a variety of sensory experiences to enhance attention span, organize body movements and expand play skills.

When: Mondays, 9:30-11:00am

Staff: Physical and Occupational Therapy available

Fun Factor II

A sensorimotor group for children ages 4½ years and up who demonstrate difficulty with sensory modulation/regulation, motor planning and body awareness. This group will be designed to provide a variety of sensory experiences that will incorporate all sensory areas to improve effective participation in their overall environment.

When: Mondays, 12:00noon-1:30pm

Staff: Physical and Occupational Therapy available

Summertime Therapy 2005 Application Form
Application Deadline – Friday, May 13, 2005

Child's Name: _____ Date of Birth: _____

Address: _____

City: _____ State: _____ Zip: _____ County: _____

Parent/Guardian: _____

Home Phone: _____ Work Phone: _____

How did you find out about Abilities First? _____

I am interested in the following for my child:

- | | |
|---|--|
| <input type="checkbox"/> Terrific Toddlers | <input type="checkbox"/> Feeding Group |
| <input type="checkbox"/> Therapeutic Preschool | <input type="checkbox"/> Independent U. |
| <input type="checkbox"/> School Readiness | <input type="checkbox"/> Summer Survivors |
| <input type="checkbox"/> Write Right | <input type="checkbox"/> Fun Factor I |
| <input type="checkbox"/> Community Outing Group | <input type="checkbox"/> Fun Factor II |
| <input type="checkbox"/> Individual Physical Therapy | <input type="checkbox"/> Individual Occupational Therapy |
| <input type="checkbox"/> Individual Speech-language Therapy | |

Please note that therapists will screen and/or evaluate your child to determine if participation in the Summertime Therapy program will be beneficial.

Current IFSP, IEP and/or evaluation? Yes No

If yes, indicate which therapy:

- Physical Occupational Speech-Language

Indicate your funding sources: Insurance Medicaid BCMH
 Self Pay School District Other

Please note that some insurance companies may cover the cost of individual and/or small group therapy for children with a medical diagnosis and statement of medical necessity from your physician. We will assist in processing claims.

Physician's Name: _____

Does your child have a physician's prescription for any of the following therapies?

Please indicate:

- Physical Occupational Speech-Language

Please state all related medical diagnoses:

Please respond quickly, as enrollment is limited!

Please fold, tape, apply postage and return application form. If you have any questions, please contact:
Application Service Coordinator

Bettie Rountree, Ther-

513-423-9496 or 800-378-8612 FAX: 513-727-3806
Application form must be at Abilities First no later than Friday, May 13, 2005

Congratulations Graduate!

Jeffrey Michael Bloomingdale was born 6 weeks premature on Dec. 29, 1984 at St. Elizabeth Hospital in Dayton, Ohio to Donald and Connie Bloomingdale. On Jan. 3, 1985 Jeff came home to live with his parents, older sister Stephanie and older brother, Ryan in Fairborn, Ohio.



Schooling: Jeff began early intervention at the tender age of 5 weeks at Four Oaks School in Xenia, Ohio. In his first year, Jeff met lifelong best friend Joe Nartker (MVDSA member and '04 graduate). Jeff has grown up in the Fairborn school district and began attending public school at Five Points Elementary School in Sept. of 1990. Jeff progressed through Baker Jr. High School and in 2000 Jeff began his final four years of public education at Fairborn High School.

Activities: Jeff participated in Special Olympics in Greene County while at Five Points School, and has played baseball in Kettering's KABC Explorer League for special needs children since its creation in April 1995. In Sept. 1999 Jeff became a charter member of Boy Scout Troop 144 and continued in scouting for the next four years, gathering memories and making lifetime friends. Jeff has been active in church. In 1977, Maple Heights Baptist Church in Fairborn created a special needs class so that he and other children might be part of their Sunday school program. Jeff accepted Jesus Christ as his personal Savior at this church on Oct. 17th, 1999. He is currently a member of North Central Baptist Church in Riverside, Ohio where he is an usher and has participated in dramas for the Easter and Christmas programs.

Jeff lives at home with mom and dad and is currently working part time at Greene Inc. in Xenia. His parents report that he is a wonderful son and brother as well as a fun, loving uncle to three nephews. On June 3rd, 2005 Jeff will become a graduate of Fairborn High School.

We congratulate Jeff on his achievements and especially his upcoming Graduation from high school!

Reminder notice:

For those of you who may not have returned your scholarship questionnaire to the office, please do so ASAP. Please use the envelope that was enclosed with the mailing so that it will be directed to the Finance Committee's notice. ***Thank you and a special thanks*** to so many of you who responded promptly!

Happy Birthday!

Robin Foster	May 4, 1965	Justin Vance	June 1, 1981
Joe Nartker	May 9, 1985	Jason Pinches	June 2, 1979
Julian Vagedes	May 9, 2001	Bridgitte Fannnin	June 7, 1990
Rodney Rounds	May 11, 1966	Kayley Rose McGovern	June 10, 2002
Walter C May	May 12, 1972	Rick Mosher	June 15, 1952
Christopher Simpson	May 13, 1990	Brandon Fischer	June 16, 1998
Liliana Durig	May 14, 2001	John Joseph Varmuza	June 16, 1980
Jonathan Holmes	May 17, 1994	Amanda Nicole Harvey	June 19, 1980
Phillip Weikel	May 20, 1985	Dawn Miller	June 23, 1956
Carter Suttle	May 28, 2002	Janice Brun	June 25, 1982
Victor Shambo	May 30, 1977		
Andrew Hangen	May 31, 1994		



MIAMI VALLEY
DOWN SYNDROME ASSOCIATION
1133 S. Edwin C. Moses Blvd, Suite 190
Dayton, Ohio 45408-2071



May Meeting — see page 1 for details

- **Dinner 6:30 – 7:00 pm**
- **Short business meeting**
- **Officer elections**
- **Spotlight on Talent**
- **Scholarship distribution**



Future MVDSA event details will be available following the Strategic Planning Meeting (see page 2).

Our next regular Business Meeting will be held June 16, 2005.

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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. It is up to the discretion of the editor as to what space is available, thus possibly limiting the contents. Articles should be submitted in one of two methods. The preferred method is a computer file. Articles may also be submitted in a typewritten format.

Material for consideration must be submitted to: Editor (address listed above)

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