



January 2003

DSA Press

Down Syndrome Association
of West Michigan

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Calendar

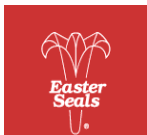
Wed., Jan. 14, 21 & 28 - Smart Signs, *Let's Play & Sign Together: Parent & Child, Birth to 24 Months*, by Melissa Burt Smith, 9-10am, East Grand Rapids Parks & Rec Dept. Call (616) 246-0884 to register.

Wed. Jan. 21 - Kent County *Early On, Genetic Awareness Workshop* by Karen Lewis, Genetic Counselor, Spectrum Health, 1-5pm, Kent ISD. To register visit www.kentisd.org/earlyon or call 616-365-2310.

Feb. 4 & Feb. 5-26 - *Smart Signs Workshops*, by Melissa Burt Smith. Call (616) 246-0884 for details & to register for these and other classes.

Wed. Feb. 18 - Kent County *Early On, Solutions for Sensory Needs of Toddlers* by Kindy Segovia, OTR, 3-5pm, Kent ISD. To register visit www.kentisd.org/earlyon or call 616-365-2310.

Sat., Feb. 21 & Mar 20 - Super Saturdays Ages 3-11, Easter Seals, 10am to 2pm. Bring a sack lunch. **Must RSVP to attend. Call Terri at (616) 942-2081.**



Board Deliberations

An article worth reprinting & sharing ----- Lois Roelse, President

Editorial Thoughts... On Being Tender

By Margaret W. Lewis, Webster Groves, MO

(Reprinted from Down Syndrome News, Vol. 24, No. 2, has been edited for content).

There is a dilemma, as an editor, in meeting the needs of the public relations impact, of proving beyond the measure of a doubt that children and adults with Down syndrome have potential - that formerly inconceivable capacities are possible for people with Down syndrome.

The dilemma is that, in striking out with our best foot forward, we sometimes run the risk of kicking, quite cruelly, some parent whose cherished child will never go to high school, never give a public talk, perhaps never even speak at all.

Continually we hear talk of stories of success, tip-top achievements. Often there is humor and gentle acceptance of imperfections, but in each of us as parents there seems to emerge that insidious seed of wanting to have, as someone put it, the best child with DS. Having conquered (we like to believe) the grief of not having the normal child we expected, we still play for the winner's circle.

And it is good to have high expectations. Good to take joy in the little triumphs, good to show a doubting public that our kids too are wunderkids. But where is the line, where is the edge of tenderness that keeps us aware of the hurt of others? The great thing we, as parents of children with DS, share with one another is the vulnerability we each inherited when our particular child was born to us. The automatic humbling came to us every one, and out of it was created a kinship unlike any other but that pain can bring.

In the end, of course, it's a matter of individuality. The final joy is in the achievement, the communication - whatever level - of each child as himself or herself. The final proof of our humanity is in the non-comparing love we can show for our children and for each other.

But, if chance has dealt you a "high functioning" kid, take a few minutes and role-play the part of the parent of a child who doesn't read, or count, or jabber hundreds of words. How do you insulate yourself from the "what did I do wrong?" feelings, the "maybe if I try harder..." feelings, the just plain jealous, wounded feelings that surge up over the triumphs of another child - particularly one close to your own child's age - and then the guilt feelings of knowing you SHOULD be taking unalloyed pleasure in the achievements of someone else's little genius.

We need to interact with one another as parents and encourage one another with reasonable expectations. Let us be sure that we are not reduced to bragging at the expense of someone else's dignity and despair. Our advocacy is for every single child born with DS, not just the cream of the crop!

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Circle of Friends

"Circle of Friends" is a social group which meets on a regular basis facilitated by the school social worker. The group consists of students with and without disabilities. The group can act as a strong support system for the student with the disability as well as give non-disabled students an opportunity to learn from, support and assist the student with the disability.



The following are steps to begin Circle of Friends.

1. Discuss the group with the classroom teacher and explain that the students may occasionally miss class time. Circle can also be conducted during lunch-time or recess.

2. Discuss the opportunity of belonging to Circle of Friends with the class (with or without the student with the disability present, depending on that student's preference).

3. Identify the ways student who sign up can participate. Examples: Read with student when own class work is completed. Call student at home to follow up on school activities, general discussion or simply to practice appropriate phone skills. Agree to meet during school hours as a group to play games, work on projects or participate in school improvement project. Invite student to birthday parties, etc.

4. Send permission form home to student who wish to sign up for Circle. Explain that their child may miss some school time. Also include a description of the planned activities.

5. Communication is important. The social worker may want to discuss positive ways of supporting the student with the disability with their peers if inappropriate behaviors occur. This discussion can lead to open communication with students if questions or concerns arise.

6. If several student sign up to participate (which isn't unusual) the group may be divided into two or three small groups which rotate.

7. Monitor the group to assure the student with the disability is seen as an equal member.

8. The emphasis of the group should be social or activity oriented activities versus calling attention to the person with the disability.

Typically the best time to start Circle of Friends is in the 2nd or 3rd grade. As the student gets older the group may take on a different purpose such as being responsible for making school sports posters, joining an after school club together or peer assistance with a school job.

A parent may choose for their child not to have a formal Circle of Friends because their child is supported by a class full of students who are already their friends. The perceived benefits of having a formal Circle of Friends is a parent's decision.

To be connected with school social workers who have facilitated Circle of Friends, call West Michigan Inclusion Network at (616) 954-9424.

(from Inclusion Solution, newsletter of the West Michigan Inclusion Network, Winter 2000/2001).



CONGRATULATIONS JIM SCARLETT

In December the Association received a donation of \$2,000 in honor of the "WHO Award - Woodworker's Helping Others" awarded to Jim Scarlett for his commitment to community service.

The award and contribution were presented by Tradeshow Incorporated at the Midwest Expo Industrial Woodworking Convention at DeVos Place.

"The Down Syndrome Association of West Michigan owes Jim a debt of gratitude for having the vision to help form the organization 18 years ago. Jim has continuously supported the organization over these many years and his service has been an inspiration to us all. This award appropriately recognizes his advocacy for individuals with Down syndrome."

Non-Profit Group Days

D&W Fundraiser for Non-Profits

D&W Food Centers, Inc. is offering the Down Syndrome Association of West Michigan an opportunity to share in their profits from customers who shop at the **Cascade, Grandville, Holland and Grand Haven** stores on Monday, Tuesday, or Wednesday, **February 2 - 4, 2004**. Five (5) percent of the sales generated by you will be donated back to the Association.

Watch your mail for your D&W coupon which you may copy and use as many times as you would like. Be sure to make copies for your family and friends.

Thanks in advance for shopping at D&W.

Disney's Special Services Can Help Make Your Dream Vacation a Reality

by Jane McNamara Thomas

If you're planning a family vacation to DisneyWorld or Disneyland, you're not alone. Millions of parents will head to sunny Southern California or Florida this year to share the magic with their children. But for parents of children with special needs, even the Magic Kingdom can lose its charm-unless you know where to turn. Disneyland Resort, Disney's California Adventure and DisneyWorld offer special services to help make sure children and adults with disabilities and their families have a magical experience. Here are a few things you should know before you go:



Ask About Disney's Special Assistance Pass - The pass provides special access for individuals with intellectual or developmental disabilities who may need assistance or who are unable to wait in long lines (individuals with mobility disabilities don't need a pass to gain special access). The pass enables a guest, and up to five members of his/her party, to enter rides and attractions at a designated location, avoiding long lines. Although the pass does not guarantee immediate access to every attraction, it can provide a shorter and more comfortable wait. Disney's special assistance pass is included in the regular admission price. Go to the guest relations lobby at the respective theme parks to request the pass.

Request a copy of *Disney's Guide Book for Guests with Disabilities* and be sure to take advantage of other helpful services available to all guest, such as the following:

Disney's Fastpass - Shortens your wait at specified attractions.

Disney's Child Switch Pass - Allows both parents to ride without leaving your children unattended. Also available to parents with older children who can't or don't want to ride an attraction.

Disney's Baby Care Center - Quiet, comfortable, air-conditioned facility for feeding or changing diapers. Also offers a wide variety of baby care supplies for purchase.

Lost Children Facility - Start your day here and learn how to avoid becoming separated. Ask about lost children stickers. Young guests can wear a sticker with their parent's name as well as cell phone and pager number included. The child's name *does not* appear on the sticker.

Ask about **Disney's Happy Hearts Days** - Disney offers guest with disabilities and their families discount tickets on select dates each year during the fall and spring. Tickets must be requested in advance.

Disney Information Hotline - California - (714) 781-7290
Florida - (407) 939-6244
(from the Advocate, newsletter of the Utah Down Syndrome Foundation, June 2003)

Parent Coffees

Call Tate Reminder at (231) 865-7493 or visit our website at www.dsawm.org for January coffees dates.



Happy New Year



DSAWM Board

President:

Lois Roelse 616-554-5410

Treasurer:

Tim Hill 616-957-4934

Secretary:

Charlene Hill 616-957-4934

Members at Large:

Laura McCarthy 231-798-8643

Jennifer Giordano 269-857-2931

Mike Frantz 616-698-0299

Michele Staal 616-842-8282

Mary Snyder 616-844-6051

Tate Reminder 231-865-7493

New Parent Coordinators

Shelly Benham 616-285-0011

Mary Snyder 616-844-6051

Librarian

Lois Roelse 616-554-5410

Well Wishes Club

Sue Lenhardt 616-365-8811

Call if you know of someone with Down syndrome who is being hospitalized.

Disclaimer Policy Statement

DSAWM is a volunteer group consisting of parents & caregivers of individuals with Down syndrome. The *DSA Press* is written on a volunteer, non-professional basis. This newsletter reports items of interest relating to DS in an attempt to create an optimistic outlook and attitude. DSAWM does not support or endorse any particular regimen, treatment, political or religious view and does not endorse any individuals or organizations referred to herein. DSAWM is an affiliate of National Down Syndrome Society.

DSA Press is published nine times a year by the Down Syndrome Association of West Michigan. Editor: Char Hill, Phone (616) 957-4934, Fax (616) 974-9612, E-mail dsawm@iserv.net

"Just when you think you have learned what you need to know in life, someone truly special comes into it and shows just how much more there is."

- Author unknown

Lending Library

The Association has an extensive lending library of books and videos on such topics as health, education, inclusion and support.



To order items from the library, call Lois Roelse at (616) 554-5410 or visit our website www.DSAWM.org and access the library data base by author, title, publisher or topic. The books will then be mailed to you.

Resources

The 2003-04 Edition of the *Michigan Directory of Service Providers for Infants, Toddlers, and Students with Disabilities* will soon be available from the Center for Educational Networking (CEN). The directory contains information about administrative personnel who provide educational and other services related to the following:

- Michigan's infants and toddlers ages birth to 3 with special needs.
- Michigan's students ages 3 to 26 with disabilities.

The directory will also provide details about specific services that state

and national community agencies, associations, and organizations provide to these individuals and their families.

The directory will be available for download at www.cenmi.org or to order a copy, call CEN at (800)593-9146 ext 4.

The American College of Emergency Physicians and the American Academy of Pediatrics recommends that families of children with complex health needs complete an "**Emergency Information Form for Children with Special Needs.**" This two page form is designed to give a quick overview of your child's needs to professionals in an emergency. It gives a complete look at the history, diagnoses, equipment needs and typical protocols for the child. Parents can decide where the form could be distributed, but it is especially helpful for first responders in the case of an emergency. The form is filled out with the assistance of your child's primary care physician. Call the ARC/Advocacy Resource Center in Ottawa County at (616)738-8570 to obtain a copy of the form.

Bowling at Fairlanes Grandville

Saturday, January 17
1:00-4:00pm

Special Needs
Youth Group
(age 13 and up)

Come join us for an afternoon of entertainment and more.



Call Chris or Teri at
(616) 538-2600 to register.

-- Next Event --
Saturday, February 14
1-4pm

Youth & Adult Activities

Topsoccer - practices monthly throughout the winter. You can join at anytime. Call Craig or Laurie Wilson at (616) 245-6973 or e-mail them at 920Wilson@comcast.net for details.

GYMCO'S Special Needs classes are designed to offer the benefits of MOVEMENT EDUCATION to any student who may not be accommodated in our regular classes. Gymco offers free evaluations for your special student to determine whether they should be placed in a mainstream class, special needs class, or if private lessons would be most beneficial. Call (616) 956-0586 to schedule yours today.

Kentwood Therapeutic Recreation Program - The following is a sample of activities offered by the Kentwood Parks & Recreation Department.

- **Leisure Club** - *Thursdays, on-going*
- **Super Saturday Trips** - *TBD*
- **Snow Dance** - *Friday, Feb. 13 from 6:30-9:30pm*

Visit www.ci.kentwood.mi.us or call Val Romero at (616) 656-5275 to obtain the detail of these activities or to be added to the mailing list.

Easter Seals

SUPER SATURDAY, Ages 3-11 are held monthly from January through May (see Calendar on page 1 for upcoming dates). Super Saturdays are designed to provide kids with disabilities and their siblings exciting activities and offer respite for their parents.



WINTER SENSORY CAMP, Ages 3-6 will be offered in a six-week session beginning the week of January 12 and ending the week of February 16. Camps will meet on Monday afternoons from 3:00-4:30pm and Wednesday mornings from 9:30-11:00am. The cost is \$200 for once a week and \$400 for twice a week.

Future sessions of Sensory Camp are March 1 - March 29 (5 weeks), April 12 - May 24 (7 weeks, off the week of April 5).

INDIVIDUAL OCCUPATIONAL THERAPY, Birth & Up is available Monday mornings and Wednesday afternoons on a weekly basis. The cost is \$35.00 per session or \$210.00 for the 6 week term which begins the week of January 12 and ends the week of February 16.

Call Terri Cooper at Easter Seals (616-942-2081) to receive registration forms for the above classes.

Area Conferences and Workshops

ALTERNATIVES TO GUARDIANSHIP

HOSTED BY ARC/ADVOCACY
& RESOURCE CENTER

The workshop will be held on Thursday, February 5 from 2:30-4:30pm and again from 6-8:00pm at Ottawa ISD, Port Sheldon Street, Holland.

Dohn Hoyle and Kathleen Harris will discuss what options are possible instead of guardianship and offer information and resources to assist parents to make plans for the future. For more information and to register call the ARC at (616) 738-8570.

MAKING RESULTS COUNT MICHIGAN COUNCIL FOR EXCEPTIONAL CHILDREN

The 64th annual conference will be held Wednesday, February 25 through Friday, February 27 at the Grand Plaza Hotel, Grand Rapids. Visit www.michigancec.org for further information.

THANK YOU

The Association would like to express our appreciation to Schuler Books & Music, the volunteers who worked the many shifts and the customers of Schulers for supporting the Association. We earned over \$2,500 through your efforts! We would also like to thank Sherry Alexander, DSAWM member, for her efforts in coordinating this event.

The following classes are free of charge and are offered by Pine Rest Christian Center for Developmental Disabilities, 300 68th Street, Grand Rapids.



For more information and to register for these classes, please call Susie at (616) 281-6364.

SIBS GROUP

Group A - For siblings, ages 7-11, of children with development disabilities. Group B - For siblings, ages 12-15, of children with development disabilities.

The goal is to provide a friendly and safe environment for siblings where they can share experiences about their lives without the fear of being teased or rejected.

Group A meets Wednesdays from 4:00 - 5:15pm for eight bi-weekly sessions beginning January 14 and ending April 21. Group B meets Wednesdays from 4:00 - 5:15pm for eight bi-weekly sessions beginning January 21 and ending April 28.

FEELINGS GROUP

For children and adolescents with mental impairments, ages 10-17.

The goal is to help participants identify emotions and develop a positive self image.

Group meets on Thursdays from 4:30-6:00pm for eight weekly sessions from January 15 through March 4.

ANGER MANAGEMENT & CONFLICT RESOLUTION

For children with development disabilities, ages 8-12.

The goal is to help participants recognize and manage their anger by using verbal conflict resolutions and strategies.

Group meets Wednesdays from 5:30-7:00pm for six weekly sessions from January 14 through February 18.

Speech Therapy Available

individualized, professional speech and language therapy services are available for your child on varying schedules to fit your and your child's needs. Linda A. Kelley, MA, CCC-SLP, a speech and language pathologist for 25 years, provides quality therapy that assists each child in reaching his or her individual full potential in communication skills. Parent involvement is viewed as essential and therapy is planned accordingly.

Therapy sessions are available for 20 weeks this winter - from January 5 through May 28 - Thursday afternoons/evenings and Friday days. Parents may choose once or twice per week, twice per month, or once per month schedules. Sessions are individual and 45+ minutes in length and are held at 2566 Woodmeadow SE, GR (near the intersecting of 28th St. and Breton Rd.).

A commitment is required for this program. Contact Linda at (616) 260-3013 or lkelley55@hotmail.com (include "speech interest" as topic).

SPECIAL OLYMPICS MICHIGAN 2004 State Winter Games



February 3 - 6 Traverse City

Quick Facts -

- ◆ Over 1,000 athletes
- ◆ 700 volunteers
- ◆ Alpine skiing at Schuss Village
- ◆ Snowboarding at Schuss Village
- ◆ Cross-country skiing at Schuss Village
- ◆ Snowshoeing at Grand Traverse Resort
- ◆ Figure skating in compulsory and freestyle at Howe Arena
- ◆ Speed skating at Howe Arena

Visit www.somi.org/index.html for further information.

gRACiE'S 2003

5k Run/Walk*Chili Cook-Off*Birthday Bash

Our heartfelt thanks to Jill Westcott, family friend of Eric, Kyle and Gracie Retan, for organizing and hosting the 2nd annual event to benefit the Association. Last year, in conjunction with WORLD RUN DAY, 50 people came together for fun food and raised over \$900 for DSAWM.

This year over 100 people participated and \$2,050 was raised. Participants, both young and old, ran, walked or strolled 5 kilometers through the streets of Sparta. The celebration continued after the race with a chili cook-off and party to celebrate Gracie's 3rd birthday.

We salute Jill for her outstanding fundraising efforts for the Association and more importantly for her support for Gracie, Eric and Kyle and undertaking to promote public awareness and acceptance of Down syndrome in her community.



Gracie, Kyle & Aubrey Retan

Birthday Banns



January

1	Isabela Pena	1
1	Kelly Neathery	1
9	Eric Marlink	17
10	Philip Kisielewski	3
10	Curtis Playford	16
11	Jillian Alexis Katke	3
12	Kyle Tabler	11
13	Cody Karel	6
19	Jonathan DeYoung	8
20	Stafanie Morton	14
24	Brendon Busch	1
27	Joseph Awine	3
28	Isabelle Russo	3
29	Colin VenderVeen	8
30	Leo McNamara	14
31	Erin Wesche	20
31	Christopher Schleben	7
31	Colin Hough	2
31	Jessica Owen	15