



## Five Things Parents of Children with Special Needs Should Know

Reprinted from the May 2001 ChildCare News publication

Parenting is often a stressful job, juggling children's schedules, car-pools, activities and homework can wreak havoc on any home. If you have a child with special needs, you may be adding therapy appointments, school management issues, doctor's appointments and many more to the mix. You can easily become worn out, over-stressed or even depressed. Since your child relies on you, it is important for you to stay healthy both physically and emotionally. What follows are five simple common sense steps to help you keep yourself feeling confident and strong.

**1. Seek out support.** Don't wait until you are overwhelmed and struggling to look for help. Find people who have children with similar special needs. You will be surprised at how much help, support and

information you may receive from them. In your community, check with your school district to see if they offer a Special Education Parent Teacher Association (SEPTA) or similar



*...your personal needs should not be swept aside while your child is growing up.*

support group. Even if members have children with different needs than yours, you will find many common topics to discuss. Check your library or online for national organizations that deal with your child's disability. Often, they offer support for parents through conventions, workshops and publications. There are online groups and email lists that deal with virtually every disability. People are only too

willing to share their experiences and offer advice, tips and resources. Support can come in many forms and help you in ways you don't expect. **2. Take time for yourself.** Even if you feel pressed for time, you need to carve out time to focus on yourself. Set aside your daily chores or work for a little while. Take an hour a day or even once a week and do something for you. Exercising, getting a manicure or visiting the local park or place of interest can be refreshing and serve to re-

new your perspective. Don't put off things you want to do until your child is older or you feel he doesn't need you as much. By fulfilling some of your needs, you will be happier and more able to tackle issues that come your way.

**3. Cultivate friendships.** You and your child will both benefit if you make the effort to meet and get to know your neighbors and their children. If your child is in a special school

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### TDSN Officers

- **Chair**— Leigh Menconi
- **Co-Chair**— Allison Jordan
- **Secretary**— Ann Garrett
- **Treasurer**— Billy Zahn

## Exceptionally Good Advice for Life

*This article was previously published in the Sept/Oct 2001 TDSN newsletter by Rebecca Corbin. She received the excerpt via an email. It is from Exceptionally Good Advice for Life for Living in the New Millennium, from his Holiness the Dalai Lama.*

1. Take into account that great love and great achievements involve great risk.
2. When you lose, don't lose the lesson.
3. Follow the three R's: Respect for self, Respect for others, and Responsibility for all your actions.
4. Remember that not getting what you want is sometimes a wonderful stroke of luck.
5. Learn the rules so you know how to break them properly.
6. Don't let a little dispute injure a great friendship.

7. When you've made a mistake, take immediate steps to correct it.
8. Spend some time alone every day.
9. Open your arms to change, but don't let go of your values.
10. Remember that sometimes silence is the best answer.
11. Live a honorable life. Then when you get older and think back, you'll be able to enjoy it a second time.
12. A loving atmosphere in your home is the foundation for your life.
13. In disagreements with loved ones, deal only with the current situation. Don't bring up the past.
14. Share your knowledge. It's a way to achieve immortality.
15. Be gentle with the earth.
16. Once a year, go someplace you've never been before.
17. Remember that the best relationship is the

- one in which your love for each other exceeds your need for each other.
18. Judge your success by what you had to give up in order to get it.
19. Approach love and cooking with reckless abandon.

*Editor's note:*

*Rebecca wrote this article to emphasize the point that "our children with Down syndrome can often be great little ambassadors to demonstrate the value of this prescription to achieve happiness in life". A pastor at Milwaukee Children's Hospital where Rebecca's son was born told her "you know, the Buddhist religion has great respect for people with Down syndrome. They bow out of respect. Your son has so much love in his heart". Rebecca felt very comforted by this and chose to share it with readers. Hopefully, eight-  
een months later, others reading this article will gain comfort and insight as well.*

## Notes from the Board

### Board Minutes from the January and February meetings

The January Board meeting was facilitated by Betsy Upchurch. Designated expenditures were approved for the year 2003 as long as there are volunteers to coordinate activities.

- △ Expenditures include: Annual Donor Letter, Banquet, Buddy Bowl, Buddy Walk, Child Care, Christmas Parade, Holiday Party, New Arrival Packets, Newsletter, Picnic, Scholarship

Fund, SibShops, Spanish Book, Sunshine Fund, Teacher Grants, and Two Teen Dances.

Highlights from the February meeting include:

- △ As of January 23, 27 members have elected to become registered.
- △ The Board is pursuing other printing possibilities for the newsletter.
- △ The New Parent Book will be printed again in a Span-

ish version.

- △ TDSN will sponsor a Teen Dance in April.
- △ The TDSN Family Picnic is tentatively scheduled for May 17th.
- △ The Banquet has been postponed until next Spring.
- △ The next Board meeting is scheduled for March 3rd.

*The TDSN Board meets the first Monday of every month.*

## Generosity and Support

### Family Donation

Bill and Denise Ryan made a generous contribution to Triangle Down Syndrome Network. They are the parents of two beautiful girls, Olivia and Victoria. TDSN sincerely thanks the Ryan family for their considerate support.



### Carolina Communication Project

Dear TDSN families,  
Thank you for your continued support of the Carolina Communication Project which is studying the development of speech and language. We have broadened the scope of the project to include boys who have Down syndrome and are 3 to 12 years of age. The study is being conducted by the staff from the Frank Porter Graham Child Development Institute at the University of North Carolina at Chapel Hill. If you would like

more information or would like to enroll, call toll-free 1-877-696-5797 or email [kathlene\\_anderson@unc.edu](mailto:kathlene_anderson@unc.edu). Thank you again for your support of this exciting project.  
Warmest Regards,  
Kathleen Anderson, M.Ed.  
Project Coordinator, Carolina Communication Project

*Received via TDSN email on January 29, 2003*

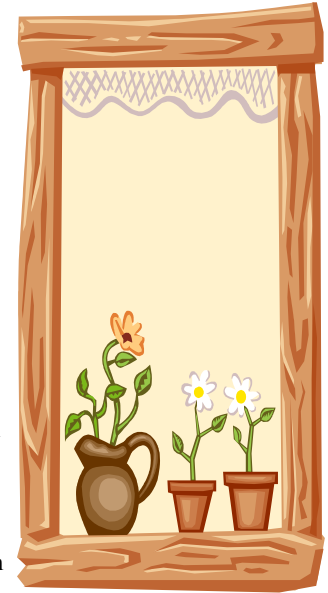
# TDSN Calendar Items

## MARCH

- \* TDSN is co-sponsoring an IEP workshop with the ECAC in lieu of the monthly Parent Meeting from 9:00 a.m. until 1:00 p.m. Please visit ECAC's website [ECAC-parentcenter.org](http://ECAC-parentcenter.org), or call the TDSN information line at 835-3739 for details about location. Childcare will not be provided.
- 3/3 Board Meeting at Cary Travel at 7 p.m.
- 3/24 Mom's Night Out ( Meet at Bahama Breeze on Wake Forest Road. See page 5 for more details. RSVP Stephanie Bednar @ 752-0313)

## APRIL

- 4/5 Spring Fling Teen Dance ( Dance will be held at White Plains Church from 7 p.m. until 10 p.m. Contact Dona Hess for details at 319-9975)
- 4/7 Board Meeting at Cary Travel at 7 p.m.
- 4/19 TDSN Parent Meeting ( White Plains United Methodist Church from 10 a.m. until noon Lillie Delott will teach a yoga class for parents. Childcare will be provided for children over one year of age)
- 4/28 Mom's Night Out (Meet at Maggiano's Little Italy at Streets of Southpoint. See page 5 for more details. RSVP Stephanie Bednar @ 752-0313)



*For add'l info on activities  
call the  
Information Line at 835-3739  
or visit the  
TDSN web site at  
[www.Triangledownsyndrome.org](http://www.Triangledownsyndrome.org)*

## Birthday Superstars!

### MARCH SUPERSTARS!

- 3/4/01 Zachary Coghill
- 3/20/01 William Reid Holmes
- 3/20/94 Benjamin Seagroves
- 3/21/01 Emily Kouder
- 3/22/01 Tempest McKenzie
- 3/24/00 Emily Lanning
- 3/24/93 Sarah Goldberg
- 3/29/00 Olivia Ryan



### APRIL SUPERSTARS!

- 4/2/99 Christopher Corbin
- 4/4/84 Kerry Hagner
- 4/10/00 Felipe Franischine
- 4/11/94 Kevin Iannucci
- 4/27/01 Taylor Bunch

*If your child has a birthday coming up and you would like to include it in the newsletter, please contact Leigh Menconi at 856-0391 or [lmnconi@earthlink.net](mailto:lmnconi@earthlink.net).*

# Treasures!!!

## What a Treasure

Submitted by Michelle Schwab

*This is a paper written about a five year old who happens to have Down syndrome. The author is a fourth grader at The Raleigh School named Mary. She is a friend of our family. The writing prompt for this assignment was to write about a "treasure". This is what she wrote.*

"Megan. What? How can she be a treasure? They aren't even related." you might say. But Megan is a treasure. She proves the saying you don't have to be paid to be a teacher. She teaches us through a disease, the disease of Down syndrome.

She teaches us not about our ABCs, but an attitude, a new point of view. A new light that without her we may not have

found. I call it love. Not the love you feel towards your family but a deeper fondness that I can't explain. Whether she is singing, dancing, or reading a book she can always make you smile.

She can accomplish anything she wishes to. Nothing is impossible now! Megan has learned to deal with the nice and the rude. And I treasure her for those reasons. So next time you see someone with Down syndrome smile, wave and you will discover they aren't that different at all.



***Nothing is impossible now!***

## If I have special needs, remember...

*Taken from the book, Listening to the Littlest, by Ruth Reardon.*

They are special, but I am not. I'm not a "special child" but a child with special needs. Be sensitive, and make allowances. But whenever possible, treat me like all the rest. Don't let those special needs be all you see of me. Give me the dignity of living with the same rules as others. Not set apart or different, except where I must be. Keep me and others from using handi-caps.

## The Central Directory of Resources

The Central Directory of Resources (CDR) is a resource center available to parents, families, and professionals statewide. This computerized resource center provides access to important information and materials about:

Δ Services, agencies, and other resources

Δ Specific health problems or disabilities and handicaps

Δ Parent support programs throughout the state and nation

Δ Assistive technology (devices and services that



help people with disabilities in their daily lives)

Contact The Center Directory of Resources through their toll-free number. 800-852-0042 (TDD/VOICE)

Additional information can be accessed at [www.fsnn.org](http://www.fsnn.org)

## Durham Parks & Recreation Programs for Special Populations

Durham Parks and Recreation Department has a Special Populations/Inclusion Division that has developed many programs and opportunities for individuals with disabilities. They state "Special Populations/Inclusion Division seeks to offer diverse recreational and leisure programs and opportunities for persons with physical and developmental disabilities. We provide tailored programs for participants based on their

disability as well as assist in making reasonable accommodations for persons with differing abilities to participate in any Parks and Recreation program. Please contact the coordinator or instructor of the program needing accommodations when registering. All Special Olympics Programs listed are FREE of charge, however, other programs may include a fee."

For more information please contact:

Durham Parks and Recreation Department  
Special Populations/Inclusion Division  
Jennifer Hanspal or Kristen Randall  
101 City Hall Plaza  
Durham, NC 27701  
Phone: 560-4355  
Fax: 560-4021  
Website: [www.ci.durham.nc.us](http://www.ci.durham.nc.us)

*See page 5 for list of programs*

## Wanted: Chairperson for the Fifth Annual Buddy Walk

Triangle Down Syndrome Network is looking for an individual to organize the Fifth Annual Buddy Walk. If you have ever attended the TDSN Buddy Walk you know how much fun it is. Before all of the fun can be had, however, much



***We want you!!!***

work must be done. Fortunately, there are many willing volunteers in this group to share the work. We still need someone to volunteer to head this dedicated group of helpers. The Board is open to

changes for this event, so if you have any ideas and are looking for a great way to be involved, please contact Leigh Menconi at 856-0391 or by email at [lmenci@earthlink.net](mailto:lmenci@earthlink.net). We ***must*** have someone to coordinate and organize the Fifth Annual Buddy Walk or sadly this wonderful event may be cancelled.

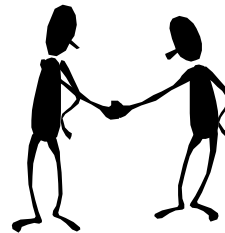
## TDSN Monthly Events

### Mom's Night Out

Mom's Night Out or MNO is an opportunity for moms to get together once a month to share stories, support each other and gather resources and information from one another. Most meetings occur at a local restaurant but are sometimes hosted at someone's home. Stephanie Bednar coordinates the meetings for each month. They are posted in the calendar with location and time listed. Please contact Stephanie at 752-0313 or by email at [sbednar@ctc.net](mailto:sbednar@ctc.net) to RSVP or get more information.

The March 24th meeting is at Bahama Breeze at 3309 Wake Forest Road in Raleigh and the number is 872-6330.

The April 28th meeting is at Maggiano's Little Italy at the Streets of Southpoint, 8030 Renaissance Pkwy in Durham and the number is 572-0700.



*MNO and TDSN Parent meetings occur each month*

### TDSN Monthly Parent Meetings

The Triangle Down Syndrome Network sponsors a parent meeting each month. The meetings generally occur at White Plains United Methodist Church located in Cary. The meetings are posted in the calendar. Childcare is usually provided however special circumstances may not warrant it at times. Please access the TDSN website at

## Durham Parks and Recreation Programs

The Special Populations/Inclusion Division through the Durham Parks and Recreation offers Inclusive Intersession and Fun Days Opportunities for children ages 6-12 through providing an inclusion specialist or sign language interpreter during intersession hours. Inclusion is when everyone, children and adults, with and without disabilities, participate side by side in recreation programs and events. Inclusive intersession is open from 7:30 a.m. through 6:00 p.m. Monday through Friday. The fees are \$75.00 for city residents or \$82.00 for non-city residents. The fee per day is \$15.50 for city residents and \$17.50 for non-city resi-

dents. Inclusive intersession is available March 13th through 21st and April 14th through April 18th. Contact Jennifer Hanspal, Kristen Randall or Eugene Harris at 560-4355 for more information. Additional activities and programs include the following:

△ **Special Populations/Inclusion After School Programs (ages 6-21)**- An after school recreational program for children with developmental disabilities is offered from 2:00 p.m. until 6:00 p.m. at Lyon Park Community Center located 1313 Halley Street in Durham. Cost is \$15.00 per week.

△ **Family and Friend Bowling (10 and up)**

△ **Friday Fun Nights**

△ **Buddy Tee Ball (5-13)**

△ **Therapeutic Horseback Riding Program**

△ **ARC Dances**

△ **Special Olympics Swimming, Track and Field, Power Lifting, Softball and Gymnastics**

△ **Summer Camps**

## Five Things Parents of Children with Special Needs Should Know *cont*

*Continued from page 1*

rather than the local public school, this is especially important.

Friendships made outside the realm of your child's educational environment can be especially rewarding for you, your child and the other child as well. Children learn compassion and patience when they get to know others not quite like them. By introducing yourself and your child around the neighborhood, you will make some new friends and will not feel so isolated from the community.

**4. Follow your gut instincts.** Always remember that you are the expert on your child. No one knows him better than you do. If you feel that a doctor, teacher or other professional does not understand your child's needs, find another one. Just because someone has a degree or a reputation in a particular field doesn't mean they are the right one for you or your child. The decisions you make (regarding) medical

and other professionals can have long term effects on your child's life. Make sure you are comfortable with them.

**5. Do your own research.** Knowledge is power. Don't rely on the experts to make decisions for you and your child. Think of yourself as a member of your child's team. Find out what you can about all aspects of your child's disability. Learn about the latest medical treatments and technology available. Ask to meet people who have already experienced these. They will be one of your best sources for information. Research the social and emotional aspects of your child's disability. The earlier you are informed and the more you know of pertinent information, the better off your child will be.

Parenting a child with special needs can be time consuming and at times, frustrating. Your personal needs should not be swept aside while your child is growing up. Your frame of mind plays

an important role in effective parenting and decision making. Keep these tips in mind so that you can feel content with your decisions. By following these steps, you and your family will all reap the rewards.

*Written by Paula Rosenthal. Paula founded HearingExchange.com, (<http://www.HearingExchange.com>) a community of parents of children with hearing loss, deaf and hard of hearing adults and the professionals that work with them.*



## Lending Libraries

### Parent Partners Lending Library

*Taken from the Family Support Network Newsletter*

It is quite easy to borrow books from the Parent Partners Lending Library. Just call Parent Partners at the Exceptional Children's Assistance Center office at 704-892-1321 or 1-800-962-6817 to request the book you wish to borrow or to receive a complete lending library list. Books will be mailed to you along with a postage-paid, pre-addressed envelope in which the book is to be returned to the Parent Partners at ECAC.



### TDSN/ WPCC Parent Library

TDSN and White Plains Children's Center have collected a variety of books relating to Down syndrome. These books are for parents and children. The library is open during the monthly parent meetings however, it can be accessed during the week. For more information, contact Judy Ramquist or Robyn Trueblood-Noll at White Plains. The number is 469-2217.

## Volunteer Position Available



### Duke University, Division of Pediatric Medical Genetics

Interested in sharing your family experience? Duke University, Division of Medical Genetics is looking for a Parent Consultant for the Down Syndrome Clinic. The position requires your time, talent, dedication and expertise. The Clinic meets the first Thurs-

day of every month and lasts half the day. This volunteer position is integral to the success of our clinical care and provides the opportunity to draw on various skills and resources for the support of families. Volunteer training is provided. Contact Joanne Mackey,

Clinic Coordinator at 919-681-1945 for more information. Applications will be accepted through March 15th, 2003.

*"Unshared joy is an unlighted candle"  
Spanish Proverb*

## Upcoming Special Events

### Birth to Three Resource Support Group

Birth to Three Resource Support Group is held the third Tuesday of every month from 7:00 p.m. until 9:00 p.m. at Shigley Family Services, Chatham Building, 3716 National Drive in Raleigh. For directions or to have a map e-mailed or mailed to you, please contact Family Support Network at [www.familysupportonline.com](http://www.familysupportonline.com) or call 919-662-4600.

### Calendar of Spring Meetings

**3/18/03** - Nancy Pippin, Lead Pre-school Case Manager- Transition from Early Intervention to Preschool

**4/15/03** - Open Discussion and Community Resources

**5/20/03** - Patti Beardsley, Director, Early Intervention Division, Wake County Human Services

### Spring Fling Teen Dance



Put your dancing shoes on...the Spring Fling Teen Dance is quickly approaching. The date is April 5th

from 7:00 p.m. until 10:00 p.m. at White Plains United Methodist Church located on Maynard Road in Cary. All middle and high school students are welcome. A DJ and pizza will be provided but you must bring the fun and excitement. For more information or to volunteer, please contact Dona Hess at 319-9975.

### Coffee House

Resurrection Lutheran Church in Cary and Good Shepherd Lutheran Church in Raleigh

### Coffee House *cont*

are hosting a "Coffee House" for teens and adults with special needs. The get-together will be held twice a month with the church's alternating in hosting the events. Friends and families are also invited to join the group for live music, refreshments, and fellowship. Admission and refreshments are free. The Coffee House occurs from 7:00 p.m. until 10:00 p.m. Locations and dates follow below. Please feel free to attend either or both each month.

#### Resurrection Lutheran Church

107 Lochmere Drive W  
Cary, NC 27511

Contact John and Kathy Sherman  
at 467-2090

March 14 & April 11

#### Good Shepherd Lutheran Church

7000 Creedmoor Road  
Raleigh, NC

Contact Gail Vaughn at 847-8183  
March 28 & April 25

## Newsletter Policy

**General Information:** TDSNews is published bi-monthly by the Triangle Down Syndrome Network, 109 Raphael Drive, Cary, NC 27511. Current circulation is over 550 issues. You can view the newsletter via the TDSN web site. Robyn Trueblood-Noll is the editor of the newsletter. Her e-mail address is [rocknrobyn2@yahoo.com](mailto:rocknrobyn2@yahoo.com).

**Change of Address:** TDSNews is mailed 3rd

class bulk-rate and will not be forwarded if you move. Please send address changes to Leigh Menconi at [lmconci@earthlink.net](mailto:lmconci@earthlink.net) or leave a message on the TDSN Information Line at 919-835-3739.

**Deadline:** Submissions to the newsletter are due by the 12th of even numbered months. Any information received after that will be considered for the next newsletter.

**Submissions:** Submit ideas, articles and pictures for the newsletter to Robyn Trueblood-Noll at [rocknrobyn2@yahoo.com](mailto:rocknrobyn2@yahoo.com).

**April 12th** is the deadline for the May/June newsletter.

## TDSN Information

### TDSN Website

The TDSN's website at [www.triangledownsyntax.org](http://www.triangledownsyntax.org) was established in January 2000 as a resource for our families and professionals that assist and support us with the well-being of our children. To include stories about your children on the site contact Patti Dudek at [pdudek@ipass.net](mailto:pdudek@ipass.net). Indicate if you have photographs that can be posted.

We also provide an e-mail list for those who would like to stay in touch and share information about local resources.

To subscribe, send an e-mail to [TDSN-subscribe@yahoogroups.com](mailto:TDSN-subscribe@yahoogroups.com).

### Newsletter now available on the Web!

The newsletter can be viewed on the TDSN website. Information on how to download the Adobe Acrobat viewing software that you will need is also on the site. If you would like to receive a notification via email when the newsletter is available to view rather than receive a hardcopy in the mail two weeks later, please email [lmconci@earthlink.net](mailto:lmconci@earthlink.net) with your full name and email address.

The TDSN Website address is  
[www.triangledownsyntax.org](http://www.triangledownsyntax.org)

### TDSN Information Line 919-835-3739

Get the latest information about TDSN meetings and other activities and events by calling our new information line. A member of the TDSN Board will retrieve the messages and return calls as soon as possible.

### Special Note:

Leigh Menconi has a new email address at [lmconci@earthlink.net](mailto:lmconci@earthlink.net)



# TDSN

Triangle Down Syndrome Network  
109 Raphael Drive  
Cary, NC 27511

Phone: 919-835-3739

## TDSNews

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**We're on the Web!**  
[www.triangledownsyndrome.org](http://www.triangledownsyndrome.org)

## “In the Know” about TDSN

Triangle Down Syndrome Network is a 501(c)(3) non-profit organization. There are no fees for our support services but we need your tax-deductible donations to make our programs successful. Volunteers are always welcome. Our membership includes both experienced and inexperienced parents, as well as concerned professionals, friends and relatives. We respect the privacy of the individual and the family. The purposes of TDSN include but are not limited to:

△ acknowledging the diversity of all individuals by providing an open and free information exchange of traditional and

alternative choices.

△ ensuring and promoting the rights, inclusion, opportunities and well being of individuals with Down syndrome.

△ providing information, educational opportunities and support for families with individuals with Down syndrome.

△ promoting community awareness and action, to inform the public about Down syndrome.

△ promoting research into areas that will enhance the quality of life and improve

treatment for individuals with Down syndrome.

Triangle Down Syndrome Network seeks to improve the quality of life for all people with Down syndrome. TDSN provides support, education and information for families in addition to promoting awareness of the need for inclusion and acceptance of people with Down syndrome in our community.



*There are over 350,000 people with Down syndrome in the U.S. alone.*