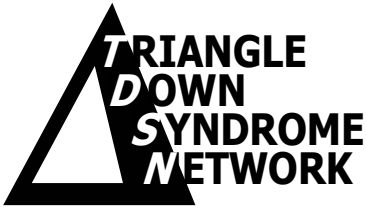


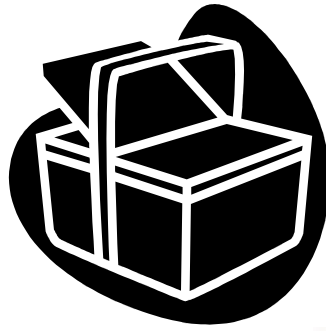
TDSN News

May/June 2005



TRIANGLE DOWN SYNDROME NETWORK

TDSN News



Come join the fun at the 2005 TDSN Picnic on Saturday, May 14 at the Preston Village playground in Cary.

The picnic will start at 4 p.m., with food to be served at 5.

This is a potluck event, so everyone please bring your favorite appetizers, entrees or desserts to share.

TDSN will provide drinks, paper products and cutlery.

Call Picnic Chairperson Patty Dudek with questions at (919) 481-9473 or send notes to [TDSN@nc.rr.com](mailto:TDSN@nc.rr.com).



# TDSN PICNIC MAY 14



A giant ball and lots of fun at last year's picnic

This is always a fun event for the kids and parents, too. There will be a clown and lots of music and entertainment for the kids starting at 6 p.m.

Preston Village has a spacious covered pavilion which is ideal for the meal. It is a beautiful setting, with a gazebo at the end of a dock on a nearby pond. The gated playground has numerous climbing, swinging, and running opportunities, with age-appropriate areas for smaller children.

The Preston Village subdivision is located off of Davis Drive in Cary. Directions are on our website at [www.TriangleDownSyndrome.org](http://www.TriangleDownSyndrome.org).

Don't miss this TDSN family event, which brings us together for a great time of fellowship, food and fun.

The rain date will be Sunday, May 15.



### Inside this issue:

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### TDSN Officers

- **Chair** – Allison Jourdan
- **Co-Chair** – Stephanie Bednar
- **Secretary** – Denise Ryan
- **Treasurer** – Billy Zahn



## Letter from the Chair

Happy, happy spring everyone! Don't you just love the color green?

The grass turning green, new green leaves growing on the trees and of course everyone having the same color of car, GREEN! Oh, happy spring.

We won't even talk about the yucky stuff that goes with it. The stuff that my darling husband and son are

dealing with now. You all know what I am talking about: allergies.

On a lighter note, things that ARE fun, and that we do love to talk about, are the warm weather and our annual TDSN picnic.

This year's picnic is scheduled for May 14. Please be sure to bring a dish and join us for a time of fun, food and friendship.

I leave you with a note of encouragement to make it through this time of spring we call "pollen season."

Everything has beauty, but not everyone sees it.

Until next time, all be well!

Sincerely,

Stephanie Bednar

TDSN Board co-chair

## "IMAGINE" — NDSS National Conference

### What is the National Down Syndrome Society National Conference?

The 2005 conference, Imagine, July 7-10, at the Fairmont Hotel, Chicago, Ill., will bring together parents, family members, professionals, teens and adults with Down syndrome, and siblings from across the country for education, networking, celebration and much more. This year's conference invites attendees to imagine the possibilities for the Down syndrome community – and how together we can make that potential a reality. The 2005 NDSS National Conference is presented in collaboration with the National Association for Down Syndrome, which serves the Chicago metropolitan area.

### Why Should You Attend Imagine?

- Actively participate in helping to shape the vision of the future for people with Down syndrome.
- Learn best practices in education, health care, employment, community living and inclusion.
- Attend the Festival of the Arts 2005, featuring the many talents of people with Down syndrome.
- Learn from and meet top experts from around the country.
- Find out about the newest products, programs and services in the exhibit hall.
- Acquire the most up-to-date information on education, research and advocacy.
- Network with more than 900 conference participants.
- Learn about resources for babies, children, adolescents and adults with Down syndrome.
- Meet and network with hundreds of affiliate leaders from across the U.S.

**July 7-10  
In Chicago**

**Call: (800) 799-4113**

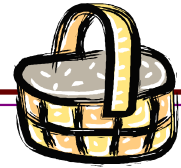
**Visit: [www.ndss.org](http://www.ndss.org)**

### Who Should Attend?

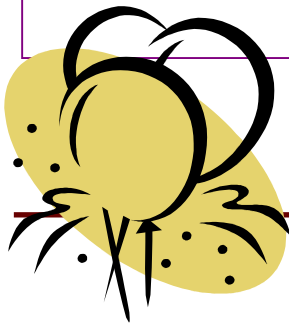
- Parents and family members
- Individuals with Down syndrome
- Siblings of individuals with Down syndrome
- Parent group leaders and advocates
- Educators and early intervention specialists
- Physicians, nurses and genetic counselors
- Psychologists, social workers and counselors
- Speech-language, physical and occupational therapists



# Calendar of Events



- May 14**      **TDSN Annual Picnic.** 4 p.m. Preston Village, Cary. Bring food, share fun.  
Contact Patty Dudek, (919) 481-9473, or TDSN@nc.rr.com. (*see page 1*).
- May 14**      **Teen to Adulthood Parent Meeting.** 9:30-11 a.m. Topic: Legal Issues and guardianship.  
Bill Weidner, a special needs attorney from the Piedmont Group in Durham. Millbrook  
Exchange Community Center, 1905 Spring Forest Road, Raleigh. Contact: Kathy Honeyman  
at (919)-878-3239 or honeymank@earthlink.net.
- May 15**      **Ice Cream Social for Families with Special Needs.** 4-6 p.m., Pullen Park Shelter #4,  
Raleigh. Free. Contact Leigh Menconi, (919) 662-4600, x257, or Leigh@familysupportonline.com.
- May 17**      **Holland Tour Series Support Group.** 6:30-8 p.m. Topic: Assistive Technology. Kris Breidel,  
Generations/Tadpole. Brooks Avenue Church of Christ, Raleigh. Free child care if reserved by  
May 10. Call Leigh Menconi, (919) 662-4600, x257, or Leigh@familysupportonline.com.
- May 23**      **Mom's Night Out.** 6:30 p.m. at the home of Paula Goldberg in Cary.  
RSVP and directions: (919) 779-3965 or egoldberg@nc.rr.com. (*see page 4*)
- June 27**      **Mom's Night Out.** 6:30 p.m. at the home of Donna Beckmann in Durham County  
(near Highway 98). RSVP and directions: (919) 682-5188 or dbeckmann@nc.rr.com. (*see page 4*).
- July 7-10**      **Imagine—NDSS National Conference.** Fairmont Hotel, Chicago, Ill.  
Call (800) 799-4113 or visit [www.ndss.org](http://www.ndss.org) for more information. (*see page 2*).
- July 29-31**      **Golden Opportunities—NDSC 33rd Annual Convention.** Anaheim, Calif.  
Call (800) 232-6372 or visit [www.ndsccenter.org](http://www.ndsccenter.org) for more information. (*see page 4*)



## May & June Birthdays



		6/3/1998	Alisah Gross	6/27/1991	A.J. Taylor
		6/7/2002	Luke Ward	6/28/1999	Christian Corley
		6/7/1985	Tinsley Hess	6/29/2002	Sarah Jo Poli
5/2/1994	Sara Green	6/10/1996	Jacob Schell	6/30/2004	Zydayavion White
5/14/1995	Matthew Howard	6/13/2001	Anna Merrills		
5/16/1999	Wesley Dunn	6/15/1997	Noah Watts		
5/18/2000	Jennifer Canon	6/16/2001	Kayla Pittman		
5/23/1956	Rhonda Burchett	6/20/1987	Ilene Whitehouse		
5/28/1999	Claudia Menconi	6/25/1992	Cara Jean Zebrowski		

*If your child has a birthday coming up and you would like to include it in the newsletter, please contact Leigh Menconi at (919)-856-0391 or [lmconci@earthlink.net](mailto:lmconci@earthlink.net).*

# You're Invited to Mom's Night Out

Let's get together for a TDSN tradition and a favorite activity for mothers — Mom's Night Out.

Come join other moms on the fourth Monday of each month for a night of fun, relaxation, and camaraderie!

Currently MNO is being held at members' homes.

Generally, we meet at 6:30 p.m., although when we meet at a home, it is okay to be late - we would rather you come late than not come at all!

Please bring either an appetizer or dessert to share and remember that babies and new

mothers are always welcome.

For additional information or to volunteer to host MNO, contact Donna Beckmann at (919) 682-5188, [dbeckmann@nc.rr.com](mailto:dbeckmann@nc.rr.com).

## May

May 23rd, 6:30 p.m. at the home of Paula Goldberg in Cary. RSVP and directions: (919) 779-3965 or [egoldberg@nc.rr.com](mailto:egoldberg@nc.rr.com)

## June

June 27th, 6:30 p.m. at the home of Donna Beckmann in Durham County (near Highway 98). RSVP and directions: (919) 682-5188 or [dbeckmann@nc.rr.com](mailto:dbeckmann@nc.rr.com)



## "Golden Opportunities" NDSC Convention July 29-31

The National Down Syndrome Congress 33rd Annual Convention — "Golden Opportunities" — will be July 29-31 in Anaheim, Calif.

*Here is a description from NDSC website:*

The NDSC National Convention has been compared to a giant family reunion, where lives are touched, relationships made and renewed, and a sense of warmth infuses the gathering. Self-advocates are empowered by real leadership opportunities. Siblings have the chance to share honestly with peers. Parents have an unparalleled opportunity to learn from renowned speakers and to meet and share with one another.

And, there's no better time for you and your family to experience that spirit than this year, when we visit exciting Southern California — just in time for Disneyland's 50th Anniversary! Bring your family and come experience the "NDSC Spirit" for yourself.



### Convention Highlights

- Friday Pre-Conference – Opportunity to participate in a 5-hour in-depth workshop about a subject important to you!
- Sharing Sessions – Informal network opportunity to interact with parents in a similar situation. Separate sessions for moms, dads, grandparents and a special session for parents whose children have a complex diagnosis.

- Friday Opening Ceremonies – A wonderful and inspirational kick-off to this great weekend! Experience the potential of individuals with Down syndrome as they perform at their best! Followed by an opening reception.

- Friday Evening Dance – Self-Advocates and their siblings dance the night away at the youth and adult mixer.

- Throughout the weekend experience the knowledge and inspiration of over 50 presenters from across the Nation.

- Saturday Evening Awards Banquet and Dance – Inspirational opportunity to experience the great accomplishments happening around the nation involving individuals with Down syndrome.

Call (800) 232-6372 or visit [www.ndsccenter.org](http://www.ndsccenter.org)

# Duke Down Syndrome Clinic

## Providing Family-Centered Care for 10 years

On the first Thursday of every month, the **Duke Down Syndrome Clinic** serves patients for everything from general check-ups to specialized evaluations. Parents choose how many specialists — from ophthalmologists to geneticists — they want their child to see on that day.

Clinic coordinator Joanne Mackey spoke at a **TDSN Parent Support** group meeting in February, giving an overview of the clinic and a bit of the history.

“It’s grown more than we ever dreamed,” said Mackey. She said the aggressive, comprehensive medical approach helps parents who are overwhelmed with information zero in on the specific needs of their child.

It also helps maximize the child’s development by assisting in getting other services in the community.

Here is a glimpse of how it came to be, its goals and what services it provides.

### History of the

#### Duke Down Syndrome Clinic

*(formerly the*

#### *Comprehensive Chromosome Clinic)*

- Clinicians were interested in collecting patients under one clinic to share expertise
- May, 1995 — at a parent organized Down syndrome symposium in the community, there were overwhelming requests from parents for a comprehensive clinic to address unmet needs.
- June, 1995 — clinicians developed goals for clinic.
- Focus was on family needs, therefore a parent consultant was recruited.

### Goals of the Clinic

- To provide comprehensive, coordinated, family-centered expert medical care for children and adolescents with Down syndrome.
- To reduce the number of trips to the hospital, by arranging for specialists who are experts in the medical problems of children with Down syndrome to see patients on the same day.
- To maximize the development of children with Down syndrome by ensuring that they receive services they need.
- To help families address behavior problems and other family issues.
- To ensure that children with Down syndrome and their families receive the community services to which they are entitled.
- To improve the care of children with Down syndrome by research.

### Resources

- Parent Consultant
  - Provide social support to parents, grandparents, siblings and family members within the clinic setting.
  - Provide families with local and national resources
  - Be available to families for assistance or discussion within the clinic setting
- Lending Library (books, articles, videotapes)
  - Maintained by parent consultant and staff.
- Referrals to TDSN support group
  - TDSN connects families of children with Down syndrome.
  - TDSN produces a New Parent Book which is given to families with a new diagnosis of Down syndrome. See [www.TriangleDownSyndrome.org](http://www.TriangleDownSyndrome.org).



**Joanne Mackey, RN, MSN, CPNP**  
**Duke University Medical Center**  
**Division of Medical Genetics talks**  
**with TDSN parents.**

### Research

- Research is an important component of this clinic.
  - Ongoing studies of the use of Cholinergic Therapy in Down syndrome.
  - Hypothyroidism in Down syndrome: Screening guidelines and testing methodology.
  - Frequency of Celiac Disease in Down syndrome in the US.
  - Infants with Down syndrome: Percent of Circulating Peripheral Blood Megakaryoblasts.
  - New onset weakness in children with Down syndrome.
  - An exploratory look into the needs of parents of a child with Down syndrome throughout the life span.
- Ongoing collaborations with outside specialties and institutions.

**For more information,  
or to schedule an  
appointment, contact  
Joanne Mackey at  
(919) 681-1945.**

# 'Medicaid Reference Desk' Wants Your Stories

**Medicaid Reference Desk** is looking for stories from people with cognitive disabilities and family members about how they have used Medicaid to increase their independence. They will collect written and recorded stories for use on [www.theDesk.info](http://www.theDesk.info), which explains Medicaid for people with cognitive disabilities. If they use your story, you will receive a free T-Shirt and \$50.

If you have a story, send an e-mail message to [stories@thedesk.info](mailto:stories@thedesk.info) or call toll-free at 1-877-431-8532. If you know someone else who has a story, forward this message to them or tell them about it. They are especially interested in stories from Hispanic families for presentation in Spanish.

The Medicaid Reference Desk is an online resource at [www.TheDesk.info](http://www.TheDesk.info) that explains Medicaid in basic terms, state by state. It gives people with cognitive disabilities, family members and advocates information about what is available through their State Medicaid Plans and waivers.

The site also gives information on where to apply for services.

They explain each Medicaid service in ordinary language. People can see and hear the information rather than read it. So far, there are about 3,000 recordings on the site.



The following 21 states are on the site:

AL CA CO DC HI IA IN LA MD MT NH NJ NY OK OR PA RI SC TN WA WI

These 10 states are in the process of analysis and will be launched by September 2005:  
AZ CT GA ID IL ME MO OH TX VT

A brochure for people with cognitive disabilities and families is now available and can be ordered in quantities by sending an e-mail to [brochures@thedesk.info](mailto:brochures@thedesk.info).

The Medicaid Reference Desk is funded by the Centers for Medicare and Medicaid Services (CMS), the Administration on Developmental Disabilities (ADD) as a Project of National Significance and the NEC Foundation of America. Members of the project team are: Steve Eidelman (The Arc of the United States), Nancy Ward (Oklahoma People First), Laurie Powers and Diann Drummond (Portland State University), Lukki Indrasutanta and Elbert Johns (TheArcLink Incorporated).

This information is from The ArcLink e-mailing list. If you would like to receive regular updates, you can subscribe to this list at

[http://chapters.thearc.org:8080/read/all\\_forums/subscribe?name=thearcleadershiplist](http://chapters.thearc.org:8080/read/all_forums/subscribe?name=thearcleadershiplist).

## Raleigh Parks & Recreation Activities

The Dragon and Wildcats Adult Social Club is run by Raleigh Parks and Recreation and caters to ages 17 and up.

There are a variety of social events scheduled for this group. For more information regarding the events planned, please call Carmen Rayfield at (919) 831-6640, ext. 6845.



Raleigh Parks And Recreation has an extensive listing of specialized recreational activities for ages 4 and up in the Leisure Ledger. Log on to [www.parks.raleighnc.gov](http://www.parks.raleighnc.gov), enter activities, click on Specialized Recreation, and then in the brown box at the top right, click on Leisure Ledger/Comprehensive Activity Listing and then scroll to pages 62-63.

If you do not have access to a computer and do not have the ledger, please call (919) 831-6640 to update your name to the mailing list and to get a copy.

### Still Looking for Summer Day Camps?

**Raleigh Parks & Rec has some:**

There are several special camps available, and the Carolina Parent March issue had listing, including websites.

Raleigh Recreation: Jennifer Tabery sent out the following memo regarding the summer camp brochure.

The summer camp booklet is available on line at [parks.raleighnc.gov](http://parks.raleighnc.gov).

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## Other Camp Ideas

Below are some other camps that might be worth checking into.

**Camp Carefree:** Visit [WWW.CAMPCAREFREE.ORG](http://WWW.CAMPCAREFREE.ORG) for more information. This camp is a 1 week sleep away camp but is limited to certain kinds of disabilities.

**Camp Tekoa:** This camp hosts a special weekend camp from May 20 – May 22 for special children and their entire families. Families get to sleep in authentic cabins, go boating, canoeing and enjoy dancing and other activities. This is located in Hendersonville and costs about \$65/person.

Check the website at [www.camptekoa.org](http://www.camptekoa.org) for additional information.

# Buddy Walk Set for October 8 at Bond Park

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We have booked Bond Park again for this year's Buddy Walk, which will be held October 8.

We're still looking for volunteers and creative ideas to appeal to sponsors and the public.

Martin Osterhout and Andrea Higgins are co-chairing this year's Buddy Walk Committee.

## WE NEED YOUR HELP!

Please consider volunteering and sharing your ideas to make this year's community awareness and fundraising event a success.



Please contact Martin at (919) 836-2934 or by e-mail at [martin.h.osterhout@gsk.com](mailto:martin.h.osterhout@gsk.com), or Andrea at (919) 217-9753 or by e-mail at [jandahiggins@aol.com](mailto:jandahiggins@aol.com).

If you have a corporate or celebrity contact that you think might be interested in contributing time or donations to the Buddy Walk, please consider sharing them with the committee.

Do you have an idea to jazz up the T-shirt design? Food? Entertainment? Don't keep quiet! Join this committee or at least share your thoughts. Let's build on previous successes and make it the highlight of the year for TDSN and the community.

Let's make 2005 a great year!

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## Newsletter Policy

### Newsletter Policy:

TDSN News is published bi-monthly by the Triangle Down Syndrome Network  
PO Box 37190  
Raleigh, NC 27627-7190  
Current circulation is more than 600 issues.

**Subscriptions:** Notices are sent via e-mail to those for whom we have e-mail addresses when a new issue of TDSN News is available to view/print at our website (see below). Printed subscriptions are mailed 3rd class bulk-rate the following week. The newsletter will not be forwarded to a new address by the post office so please send address updates to Patty Dudek at [TDSN@nc.rr.com](mailto:TDSN@nc.rr.com) or leave a message on the TDSN Information Line at (919) 788-3646.

**Submissions:** Submissions to the newsletter are due by the 12th of even-numbered months. Any information received after that date will be considered for the next newsletter. Ideas, articles and pictures for the newsletter should be sent to the editor, Andrea Higgins, at [jandahiggins@aol.com](mailto:jandahiggins@aol.com).

The next deadline is June 12 for the July-August issue.

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## TDSN Information

### TDSN General Information:

- [www.TriangleDownSyndrome.org](http://www.TriangleDownSyndrome.org)  
To include stories about your children on the site, contact Patty Dudek at [pdudek@nc.rr.com](mailto:pdudek@nc.rr.com). Indicate if you have photographs that can be posted.
- **Listsery:** 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).

- **24-Hour Information Line:** Get the latest information about TDSN meetings and other activities and events by calling the 24-hour information line. A volunteer will retrieve the messages and call you back as soon as possible.

**Directions:** **White Plains United Methodist Church** is located at 313 S.E. Maynard Road, also known as Maynard Loop, which circles Cary. **From Interstate 40:** Take exit 291 to Cary Towne Blvd. and turn right (west) towards the intersection with May-

nard. Then turn left on Maynard Road. **From Highway 54:** Highway 54 intersects Maynard Loop at two points. Turn right on to Maynard and travel southeast at the western intersection or turn left on Maynard and travel southwest at the eastern intersection. **From US Route 1/64:** Take exit 292 to Walnut Street and go north. Turn left on Maynard at the intersection of Walnut and Maynard Loop across from the Cary Towne Center Shopping Mall.



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**TRIANGLE DOWN SYNDROME NETWORK**

PO Box 37190  
 Raleigh, NC 27627-7190

Phone: (919) 788-3646

**TDSN News**

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

**TDSN Membership Enrollment Form & Survey**

Please complete the following for ALL members at your address, including children and parents. This information will help us develop programs targeted at specific age groups. Associate Members receive the newsletter free of charge and are welcome at all meetings, group events and functions. Registered members, for a nominal \$5 fee, may also vote for board members and bylaws and serve on the board. This level of membership is for any individual, family, self-advocate or professional who would like to take an active role in guiding TDSN to better serve its members.

Total Registered Members:- \_\_\_\_\_

Total Amount Enclosed for Registered Memberships ( x \$5) : \_\_\_\_\_

**Please clip and return completed form to: TDSN PO Box 37190, Raleigh, NC 27627-7190**

Full Name	Birthdate (MM/DD/YY)	Email Address	Registered Member (Y/N)	Parent (Y/N)	Profes- sional (Y/N)	Down Syndrome (Y/N)	Other Relative (Y/N)
	/ /						
	/ /						
	/ /						
	/ /						
	/ /						