



UPSforDownS

United Parent Support for Down Syndrome
Support • Information • Community

February 2012

Note from the Chair

Well, here we are already a full month into the new year and already its been incredibly busy! I feel so fortunate to be a part of this group; the support and friendships I get out of this organization provide so much more than what I put in to it. I have been involved with UPS for Downs since Cristina was a few months old....over 16 years now. In all honesty, the best part of being involved has been the amazing people we've met and the relationships we - myself, my husband, my children - have all cultivated by participating in the monthly meetings, group outings, swim parties, workshops and all else. The best thing I did for myself and my family was to get involved with UPS for Downs. But, it was also the hardest thing for me - due to time constraints and me being a bit shy and insecure. It was a challenge for to go to events and walk into a room where I didn't know anyone. However, the more often I attended, the more I began to meet many other people who were in the same boat as me. They had the same concerns and fears and hopes and dreams for their child with Down syndrome.

Very recently I was talking to some parents who have children who are about to transition out of school - meaning they are almost 22 years old. The overwhelming anxiety and fear that I hear from them all is how to keep their child social, active and connected with their friends once they are out of school. This is coming from people who have been involved and very active with their child and have educated themselves and are prepared (or as much as you can be) for their child's future. They started early on in their child's lives to connect with as many people as possible. They



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SPECIAL EVENT

EXCITING ADVANCES IN DOWN SYNDROME RESEARCH

7 p.m. on Wednesday, February 15, 2012

Prairie Center for the Arts

Details on page 6 or learn more and RSVP at

<http://dsresearch.eventbrite.com>



Looking Ahead

Saturday, February 11, 2012
Adult Social Group: Laser Tag

Sunday, February 12, 2012
Jim Gill Family Music Show

Wednesday, February 15, 2012
New Advances in
Down Syndrome Research

Friday, February 17, 2012
Bowling Prep Meeting

Saturday, February 18, 2012
Teen Scene Chicago Express
Hockey

Saturday, February 25, 2012
Parent Night Out - Dinner Theater

Friday, March 2, 2012
Parent Coffee & Playgroup

Thursday, March 15, 2012
Down Syndrome Plus

Saturday, March 17, 2012
Adult Social Club: Peggy
Kinnane's

Thursday, March 22, 2012
UPS for DownS Monthly Meeting
IEP's and Special Ed Law

Sunday, March 25, 2012
Shamrock Shuffle

Friday, March 30, 2012
Beauty & the Beast tickets on sale

Saturday, April 1, 2012
Scholarship DEADLINE

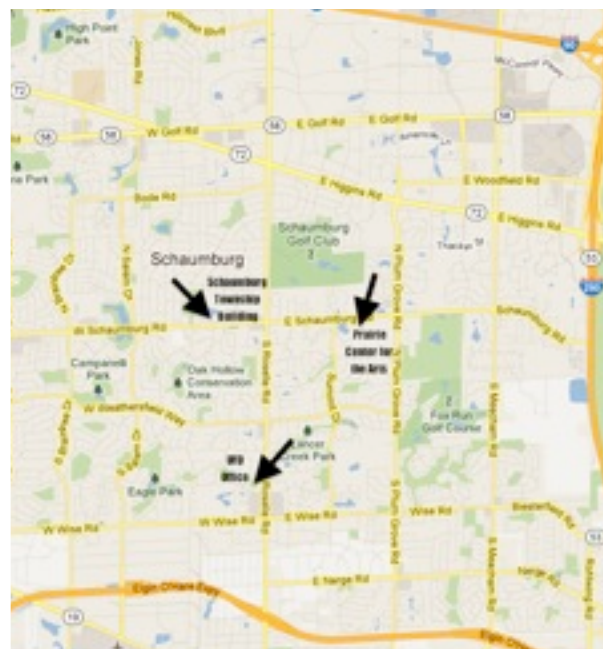
UPS for DownS

Hartford Plaza
1070 S. Roselle Road
Schaumburg, IL 60193
www.upsfordowns.org
847-895-2100

➡ got involved early and didn't wait until they needed something for their child. They have been proactive and surrounded themselves with people who are going through the same things as themselves. Life is different once your child enters high school. Everything just seems to change because their adult future is more imminent than ever. I am starting to understand this all too well now that Cristina is a sophomore in high school. Already we are discussing plans for life after graduation. The dynamics seem to change and so we must change, too. Therefore, we must all try to get our children involved in as much as possible. Get your child involved...go to your high school's sporting events, plays and whatever else might be of interest. Make sure your child is a part of your community...go for walks around your neighborhood, visit your library, go shopping at the mall, attend community events, church activities.

To me, I've identified two distinct two paths that young adults appear to take once they graduate high school. Those who have been active and connected seem to continue to be involved in classes, volunteer opportunities and jobs in the community. The students who have not been as involved in high school seem bored and not doing as much as they'd like to be doing with their life. The more I talk to people, the harder I try to make sure that Cristina will be an adult who remains an active and familiar part of her hometown. I am not sure what her future may hold but one thing I am sure of: she will be an active participant in her own life and will be surrounded by friends and activities that she enjoys.

Margherita Casale



UPS for DownS is organized and operated entirely by volunteers. This newsletter is similarly written on a volunteer, non-professional basis. Information presented here should not be construed to be objective or definitive, but represents the opinions and understandings of the contributors. We are not responsible for reliance made on any information in this newsletter. We strive to bring together those interested in Down syndrome and to create an optimistic outlook and attitude about Down syndrome for our families and others.

HOW TO INFLUENCE MEANINGFUL CHANGE:

Legislative issues that will affect the futures of you, your child, and your family



On January 27, Tony Paulauski, Executive Director of the Arc of Illinois, presented "How to Influence Meaningful Change." In order to have a voice and be heard, both in Illinois and in

Washington, it is important to become an active participant in politics. This does not mean that you must run for legislation; it means that you must get active and lend your support to those who are already advocating for empowering people with intellectual and developmental disabilities to achieve full participation in community life. Tony invited everyone to become a member of the Arc, and he offered everyone the opportunity to contact the Arc to access their resources to help improve the lives of loved ones with disabilities. Through the efforts of the Arc, legislative initiatives such as Brittany's Law, which allows a person to participate in graduation with peers but remain enrolled in school to receive services until the age of 22, can be used by students in Illinois schools. For individuals who are no longer in school, the Arc has helped secure the Community Residential Choices Program. If you have a need that must be addressed, you must make it known to those who

can legislate change, and the Arc can help you with your quest for change. Making your voice heard can seem a daunting task. However, it is important to remember that our legislators also desire change, and they have a passion to be involved in politics. They may not know much about disability policy, and that is

where your expertise is key. You will need to articulate your desires, which could include reform in education or opportunities for independent living and economic self-sufficiency. When approaching legislators, be positive and share your personal story, create a relationship. Know your facts, but be short and to the point. One visit or call to the legislator is not enough.



Tony Paulauski greets Tom Delaney and Steve Connors.

You need to maintain the relationship, make them know who you are and that you matter. Meeting with a small group in the legislator's office, giving money to a campaign, hosting a "Coffee" during the campaign, and posting campaign signage are all ways to get involved and help maintain the relationship with legislators. Knowing that they can count on you will make a legislator more likely to support your issue.

It is also important to understand political context. It is beneficial for bipartisan support. When both parties agree to support an issue, it has more likelihood to become law. This being said, not everyone will see your



Many parents came out to learn from Paulauski how use their knowledge influence meaningful change to better services in Illinois.



➔ perspective, and there may be opposition to your viewpoint. It will be important to understand the opposition to your issue and be able to defend your view, but maintain professionalism. Certain issues will be destined to create controversy, and it is best to have good data and provide information regarding the number of individuals who will benefit from your issue. Organizing a coalition may be necessary, as nothing important happens alone. Evaluate your issue to be certain it is realistic. While we are advocating change for the individual we love, we cannot forget that a law cannot be created for each individual. The issues that can realistically affect change for many will be supported by legislators. It may be helpful to get the media to cover your story or an event you host that highlights the issue you want brought to the forefront. You must also recognize that not everyone is going to support your ideas, and this does not make them bad legislators. Also, while we are all passionately involved in protecting our loved ones, how the issue is delivered to the legislators is important. Choosing who will contact the key legislator and how the issue is presented must be considered. Look for personal contacts or people who have a title or background that can help to influence your cause.

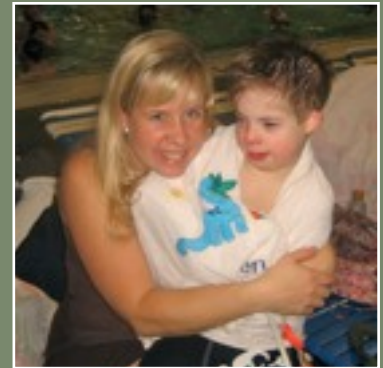
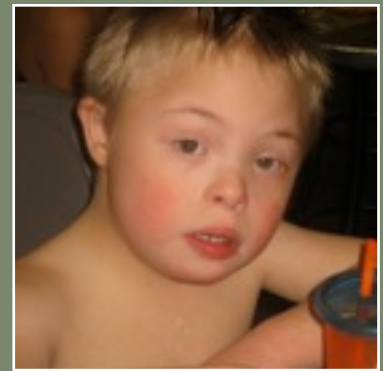
By staking a claim in getting involved with a group such as the Arc, you can influence change. Because of parents and friends getting involved, Governor Quinn has closed four state institutions and made more opportunities for home-based services and community living. Individuals with intellectual or developmental disabilities can exercise self-determination in securing living arrangements. This is an important issue that affects many. The Arc of Illinois helps thousands with disabilities be heard on both State and Federal levels. You need to take a stand, but you need not stand alone.

Get involved! Important websites to consult:

www.TheArcofIL.org

www.TheArc.org

<http://capwiz.com/thearc/home/>, www.legis.state.il.us



Summer
Swim Party
& Sibshop

2012 SCHOLARSHIPS

In 2012, UPS for DownS will award 6 individual scholarships totaling \$15,000 through our scholarship programs.



Katie MacDonald Memorial Scholarships:

- Two \$2,500 scholarships will be awarded to individuals with Down syndrome who are pursuing full or part-time educational or job training opportunities beyond high school.

- Two \$2,500 scholarships will be awarded to individual who are pursuing a junior college, undergraduate, or graduate degrees in a disability related field.



Eric Martinez Memorial Scholarships:

- One \$2,500 scholarships will be awarded to an individual with Down syndrome who is pursuing full or part-time educational or job training opportunities beyond high school.

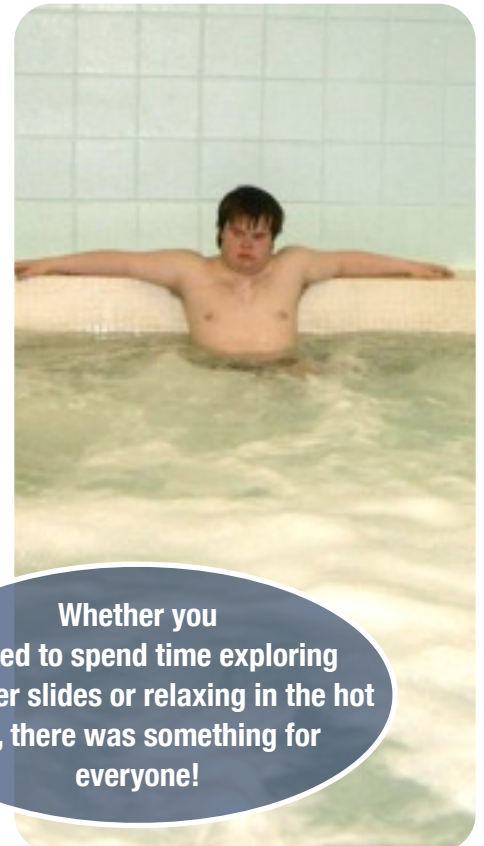
- One \$2,500 scholarship will be awarded to an individual who is pursuing a junior college, undergraduate, or a graduate degree and has a sibling with Down syndrome.



Applications must be post marked by April 1, 2012.

More details and application are available at www.upsfordowns.org

Questions? Contact Mike Reninger, Scholarship Committee Chairman, at cmreninger@upsfordowns.org.



Whether you wanted to spend time exploring the water slides or relaxing in the hot tub, there was something for everyone!

Saturday,
July 28,
2012

Jim Gill

Family Music Show



Date: Sunday, February 12

Location: Mt. Prospect Library
10 S. Emerson, Mt. Prospect, IL

Time: Show begins promptly at 2:30
Juice and cookies to follow

Cost: FREE! All are welcome!

Jim Gill has a unique approach to his concerts for young children and families. His award-winning music play has been influenced by his graduate studies in child development and belief that family play is more important to young children than music alone.

<http://jimgillshow.eventbrite.com>



New Advances in Down Syndrome Research

Wednesday, February 15, 2012

7:00 p.m.

Prairie Center for the Arts
201 Schaumburg Court, Schaumburg, Illinois

Join us to learn about the Roche Study of BP 5186582, the first potential therapy designed to improve cognition and adaptive behavior in individuals with Down syndrome.

Presenters at this exciting special event include:

Dr. Cesar Ochoa, MD, MPH, is a principal investigator for the Roche research trial examining the safety and tolerability of a new drug called RO5186582 in young adults with Down Syndrome. This new drug is the result of an exciting new line of research called Translational Research. Studies in the Down syndrome mouse model have led to the development of this drug.

Dr. Elizabeth Berry Kravis, MD, PhD, will present information regarding the mouse model, Translational Research, and the new understanding of the mechanisms behind the cognitive challenges in individuals with Down Syndrome .

Margie Doyle, from Down Syndrome Research and Treatment Foundation, will present regarding current research projects being supported by DSRTF.

Panel will be moderated by **Nancy Keck, MD**, Developmental Pediatrician and UPS for DownS Board Member.

For a map and more information, visit:

<http://DSresearch.eventbrite.com/>

*No child care is available for this meeting
REGISTRATION is encouraged, but not required.*

The presentation is expected to last one and half hours and will then allow 30 minutes for questions.



Did you know?

UPS for DownS provides sunshine to families who may be experiencing health challenges, hospitalization, or other stresses, strains, or tests of character.

If you know of a family that may be in need of some TLC from UPS for DownS, let us know by contacting us at info@upsfordowns.org. Please provide pertinent details about the circumstance, as well as name, address, phone, e-mail, hospital and/or other relevant information.

TEEN SCENE

Hockey Night!

Chicago Express

vs

Cincinnati Cyclones

WHEN: Saturday, February 18

TIME: 7:30 Game Time

COST: \$6.00 per teen with Ds
\$6.00 per 1 Adult

chaperone

\$12.00 all others

WHERE: Sears Centre Arena
5333 Prairie Stone Pkwy
Hoffman Estates, IL

Parking is \$10.00

Check out their website:

www.chicagoexpresshockey.com

Register by Monday, Feb. 13 at
teensceneexpress.eventbrite.com

Any questions, contact Kim at
korlando@upsfordowns.org or
630-404-5312

Adult Social Club

Spend St. Patrick's Day with UPS
for DownS Adult Club!

When: March 17, 2012

Time: 5 - 7 p.m.

Where: Peggy Kinnane's
8 N. Vail Avenue
Arlington Heights, IL

Who: Adults with Down
syndrome and their
friends (no parents)

Cost: \$10 per person to
put toward the bill.

Meet at Peggy Kinnane's Irish
Restaurant and Pub in
Arlington Heights for dinner.

The menu includes authentic
Irish cuisine as well as some
American favorites.

RSVP, details and map:
ufdstpattys.eventbrite.com

PARENT COFFEE AND PLAYGROUP

Please join us for this informal
get-together, with or without
your kids. **NOT** for new parents
only!

Lunch is served!

11:30 a.m. - 1:00 p.m.

Friday, March 2

Friday, April 6 or 13, 2011

Location:

First United Methodist Church,
1903 E. Euclid Avenue Arlington
Heights

Child care is provided in an
adjacent room at no cost to
you. For more information,
contact Shannon at
847-788-1138 or
kersemeier@sbcglobal.net



Down Syndrome ^{plus+}

featuring

Dr. Neal Margolis

Developmental Optometrist

Vision Skills and Learning in Children
with Down Syndrome and
Additional Behavioral Needs

Thursday, March 15th from 6:30-9:00

Location: Schaumburg Township Building

Light dinner served. Free child care provided.

RSVP by March 10th to spazerunas@upsfordowns.org.

SCOTCH DOUBLES BOWLING NEEDS YOU!

Join us as we prepare for this fun event. Gather with other volunteers for this easy, no pressure way to help out.

WHEN: 7 p.m. Friday, February 17th

WHERE: UPS for DownS office
1070 S. Roselle Road
Schaumburg, Illinois

Contact Diane at 630-483-8113 or dparadise@upsfordowns.org for details!

DS Plus is a support group of families who gather to support and educate one another regarding the unique needs of families with children who have Down syndrome and additional behavioral needs. If your child's behavior seems like something more than Down syndrome, then this group is a good resource for you. Dr. Nancy Keck, developmental pediatrician and expert in Down syndrome, behavioral disorders, ADHD, and autism spectrum disorders is the facilitator of the group. This group meets quarterly with rotating dates and locations. Free on site childcare is available at the support meetings.

To find out more information or to receive personal invitations, contact spazerunas@upsfordowns.org or call the office 847-895-2100

UPS for DownS, in partnership with Schaumburg Autism Chapter and State Representative Michelle Mussman, hosted an open forum in January with Kevin Casey, the new Director of the Division of Developmental Disabilities within the Illinois Department of Human Services. Thank you all for your interest and questions. The event was standing room only!



“If you have a six year old and only worry about a six year old’s issues, you are making a big mistake. You must look to where you are going and work to create the kind of future you want for your child.”

Kevin Casey, Director
Division of Developmental Disabilities,
Illinois Dept. of Human Services



UPS for DownS Endurance Team

DO THE DISTANCE FOR DOWN SYNDROME

UPS FOR DownS
SHAMROCK ROCKS
CHICAGO

NEW FOR 2012! UPS for DownS has a team running the Shamrock Shuffle 8k (that's just 5 miles) on Sunday, March 25! Be part of the excitement.

This race will sell out. Don't be disappointed. Register for the race, then join our team here:

<http://www.active.com/running/chicago-il/ufd-shamrock-shuffle-2012>

We can use your help at our booth during the Shamrock Shuffle Expo. Contact us with questions or to volunteer with the team: marathon@upsfordowns.org or go to www.upsfordowns.org

Bank
of America
Chicago Marathon.
Sunday, October 7

BOTH RACES WILL SELL OUT

Rock 'n' Roll Chicago
Half Marathon
Sunday, July 22

DID YOU KNOW?

UPS for DownS provides marathon and half marathon training programs for our charity athletes through the Chicago Area Runners Association. New this year: CARA training will be offered at Busse Woods in Schaumburg!

Be motivated.

Be inspired.

Be better.

Be a charity athlete.

Follow us on Twitter:
[@charityathlete](https://twitter.com/charityathlete)



Beauty and the Beast, Jr.

Rehearsals are underway

The cast is working hard blocking scenes, learning new choreography, singing their hearts out, and studying lines, as they rehearse for Disney's BEAUTY AND THE BEAST, jr., a beloved fairy tale about very different people finding strength in one another and learning how to love.

Showtimes:

Friday, April 13 7:00 p.m.
Saturday, April 14 7:00 p.m.
Sunday, April 15 2:00 p.m.

Musical Director David Zizic leads the actors in rehearsal



Tickets to go on Sale in March 30 at the Gymkhana Box Office
630-483-0330
Tickets \$10

PLEASE BE PROMPT FOR REHEARSALS.
Rehearsals Tuesdays 6:30 - 8:30 p.m. and Saturdays 12:30 - 3:00 p.m.

Little Fork. Big Fork.



When Julia was diagnosed with Down syndrome, I expected that she would have cognitive challenges and motor challenges. I expected that she would be academically and physically behind her peers. I had high

expectations of her and supported and challenged her, but I also accepted that Harvard and professional softball were out of the question. But nowhere in the literature did I read that inappropriate social behavior was a feature of Down syndrome. I made a big assumption in those early years that I could be a contributing factor to her behavior being socially inappropriate. Could it be? Do we parents treat our children like two year olds when they are ten? Are we guilty of looking at our kids as disabilities and treating them as such?

When I first started hanging around UPS for DownS, one of the parents told me "Be the change you want to see". So, that became my focus: social appropriateness. When Julia was 2, I would talk to her and treat her as 2, when she was 10, I would talk to her and treat her as 10. If she was acting improperly, I blamed myself or looked for other factors. Down syndrome did not excuse socially inappropriate behavior. I carried that into the schools and expected the same of my extended family. I would preach to them all, if you use full sentences and big words with a typical 10 year old, use big words and full sentences with my 10 year old.

Julia is now a high school junior, and how do I think I've done? Well, until a recent challenging day, I would have reported - smugly - that I'd been doing fairly well.

The day started poorly. Julia was leaving for the bus and I said "Hey, did you remember to go potty?" and she turned to look at me with an

annoyed attitude and said, "bathroom! And yes." Hours later, she came home and was telling me about her test and said "Mom, it was *willy, willy* hard" and I asked, "Well, what made it willy hard?" She glared me up and down with all the aggravation a 17 year old can muster and said, "MOM! I didn't say willy... W-I-L-L-Y...I said...*willy... R-E-A-L-L-Y!*", spelling the words to clarify how dull-witted I am. She then shouted "Get your ears checked!" and stormed away.

Finally, dinner arrived; I was so glad the day was coming to an end. I set the table as I normally do. With the family in place, I went to the oven to take out dinner and I heard Julia yelling at her father! What is going on, I thought? She was holding her fork in mid air protesting "I AM 17 YEARS OLD! I AM SICK AND TIRED OF YOU GIVING EVERYONE ELSE THE BIG FORK AND ME THE LITTLE FORK-- ALL -THE -TIME. I WANT THE BIG FORK FROM NOW ON!" My husband looked shocked and said to me *as if she couldn't hear*, "Gee, I never knew she noticed?" and with that she started again..."I KNOW! AND I WANT THE BIG GLASS TOO...!"

I never realized we gave her the little fork and little glass. It never occurred to me to do anything different. It was just automatic; grab 3 big forks and 1 little fork for Julia. Grab 3 big glasses and 1 little glass for Julia. At what point did her older sister "graduate" to the larger size utensils? Why hadn't Julia been given the same consideration?

And so began some of that dreaded soul searching. How on earth had I made such blatant errors in the confines of our home, while pushing for public acceptance and treatment at school and in the community? When did I stop seeing Julia as the person she is and start seeing her as the disability she has? What else have I been doing to disable her?

Our communities aren't the only ones that have lessons to learn, apparently so do I.

Stephanie Neri lives in Schaumburg, Illinois with her husband and 17 year old Julia, who is setting new rules as the oldest daughter in the day-to-day household, with sister Anna off at college.

PARENT NIGHT OUT

January found parents honing their knife skills as they prepared exotic pizzas at Pina's Culinary Experience in Roselle. February promises to be equally entertaining with an outing to Pheasant Run Dinner Theatre (deadline to RSVP has passed). Please look in the newsletter for future adventures or contact Stephanie at sneri@upsfordowns.org to make sure you receive personal announcements about these activities.



Parents learned knife skills and made exotic pizzas



2012 CONTACT INFORMATION

Chair	MaryLynn Cassata	847-927-8906	mcassata@upsfordowns.org
Program Coordinator	Marybeth Sanchez	773-736-7335	msanchez@upsfordowns.org
Treasurer	Peggy Grunewald	847-359-3394	pgrunewald@upsfordowns.org
Newsletter Editor	Terri Devine	708-349-9669	tdevine@upsfordowns.org
Next Chapter Book Club	Melinda Zambito	847-466-9953	mzambito@upsfordowns.org
Membership Mgmt.	Pat Fogarty	630-291-6740	MailingList@upsfordowns.org
New Parent Coordinator	Shannon Kersemeier	847-788-1138	kersemeier@sbcglobal.net
Hospitality/Refreshments	Julie Costigan	847-359-0543	JulieCostigan@sbcglobal.net
Parade	Open	847-895-2100	info@upsfordowns.org
Bowling Event	Diane Paradise	630-483-8113	dparadise@upsfordowns.org
Dinner Dance	Stephanie Neri	847-891-3224	sneri@upsfordowns.org
Adult Social Club	Laura Grunewald Shawn Fogarty	773-858-2849 847-895-2100	lgrunewald@upsfordowns.org sfogarty@upsfordowns.org
TeenScene	Kim Orlando	630-483-6903	korlando@upsfordowns.org
PreTeenScene	Julie Costigan	847-359-0543	JulieCostigan@sbcglobal.net
Education Committee	Lisa Reninger	847-301-0702	lreninger@upsfordowns.org
Down Syndrome Plus	Sandy Pazerunas	847-705-0715	spazerunas@upsfordowns.org
Scholarship Committee	Mike Reninger	847-301-0702	cmreninger@upsfordowns.org
Endurance Teams	Terri Devine	708-349-9669	marathon@upsfordowns.org



UPS for Downs

United Parent Support for Down Syndrome
Support • Information • Community

1070 S. Roselle Road
Schaumburg, IL 60193

For changes or additions to our distribution list:
MailingList@upsfordowns.org or 847-895-2100



Follow us on Twitter @ups4downs

AKBAR

Nickname: **Akoo**

Date of Birth: **November 4, 2005**



Occupation: **full time student**

Last book read: **My Farm Animals**

Favorite movie(s): **Power Rangers Samurai**

Favorite food: **Chocolate pudding**

Favorite thing about school: **Friends**

Hobby: **Socializing**

Latest Accomplishment: **I can sign my abc's and 123**

Quote: **"Time to go ... All done!"**