



UPSforDowns

United Parent Support for Down Syndrome
Support • Information • Community

April 2016

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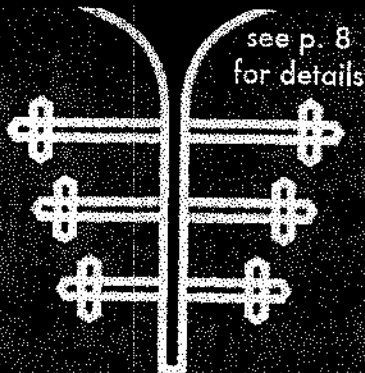
Note from the Veep.

It's just a diagnosis!

I have four children. Gavin, who has Down syndrome, just turned nine. Owen is seven, Braden is six and Aislinn is four. Shortly after I enrolled Gavin in a "school readiness" park district program, I received a phone call from the Director of the program telling me that although Gavin had been successful, it was her suggestion that he now have an aide because the fire alarms had recently been lowered, posing a temptation she thought would be far too great for Gavin.

UGH!

A year later, just before he entered kindergarten, Gavin's IEP team mentioned that after observing him in preschool, they felt he'd be better suited in a more self-contained classroom. They explained their fear that Gavin wouldn't have many friends in a gen ed setting. He was non verbal ➡



see p. 8
for details

THURSDAY
FRIDAY
SATURDAY
SUNDAY

www.ufdmusicman.eventbrite.com

1-2-3 Magic

EFFECTIVE DISCIPLINE FOR CHILDREN

Tuesday, April 19 at 7:30 p.m.

Fox Run Golf Links Clubhouse
333 Plum Grove Road, Schaumburg, Illinois

A humorous look at parenting, a serious look at discipline. With humor, keen insight and proven experience, author Dr. Thomas Phelan breaks down the task of parenting into 3 jobs:

Job #1 Controlling Obnoxious Behavior. **Job #2** Encouraging Good Behavior.
Job #3 Strengthening Your Relationships.

Get details and register for FREE:

www.123magic.eventbrite.com

At a glance...

Tuesdays & Saturdays
through April 9, 2016
Music Man Rehearsal

Tuesday, April 5, 2016
Parent Coffee & Playgroup
Adult Issues: Housing Part 2

Saturday, April 9, 2016
Parent Night Out

Thursday, April 14 - Sunday, April 17
The Music Man performances

Friday, April 15, 2016
Family Friday

Tuesday, April 19, 2016
1-2-3 Magic

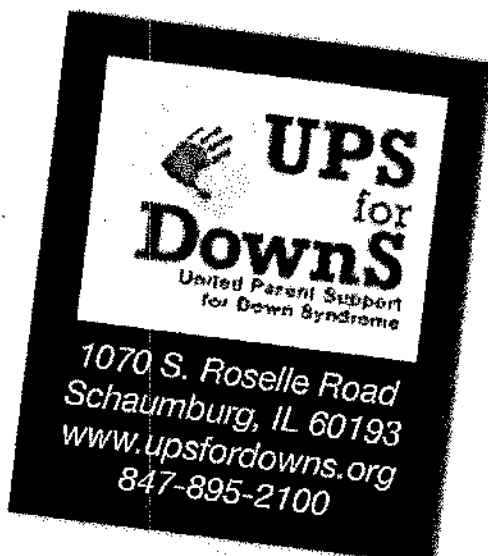
Saturday, April 23, 2016
kiDs Social Club
Teen Scene

Sunday, April 24, 2016
Early Teen Social Club

Tuesday, May 3, 2016
Adult Issues: Housing Part 3

Friday, May 13, 2016
Parent Coffee & Playgroup

Tuesday, May 17, 2016
Extended Family Q & A



and tended to play by himself more than with his peers, to watch more than engage and seemed rather aloof. He tended to be a loner and that would only be amplified in a fast paced, large general education setting.

UGH AGAIN!

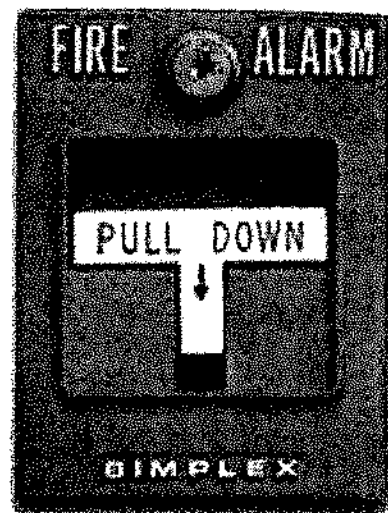
Fast forward three years. Gavin is included in third grade at the neighborhood school his younger brothers attend. I work at the school and see the boys throughout their school day. It's so satisfying to see two of my boys out on the playground - running, jumping, laughing and building friendships. They are engaged, happy and seemingly pretty popular! But it saddens me at times, when I see my other son doing the very thing those teachers described. He is often walking the playground alone, choosing not to engage with his peers, watching from a short distance away. When he sees me, he does not want to leave my side for the entire recess. I watch my other two boys playing and wonder why he chooses to play alone on the outskirts of the playground day after day.

Ironically, the very same child recently decided to pull the fire alarm at a basketball game! How could this kid be so shy on the playground yet draw such an incredible amount of attention onto himself at a crowded school event?

UGH!

The memory of what those professionals said to me about Gavin came flooding back. If only they could see what I see today, because their forecasts couldn't have been more wrong. Or maybe they were talking about my other kid. I mean, really... Braden doesn't have Down syndrome or any diagnosis at all and the description they laid out describes him to a T!

Shawna Lockner



Last month, the Family Friday event invited attendees to a special "bring a friend Friday". Families were encouraged to bring a friend or extended family member to participate in this monthly event. The children played while the adults socialized and everyone had fun! Over sixty people participated! It was a huge success and another great way UPS for DownS was able to empower our families to share first-hand the message that whether or not your family includes a person Down syndrome, we all have similar dreams, challenges and fun Friday nights!



FAMILY FRIDAY

is for families of children with Down syndrome from birth to 8 years old (and siblings of all ages). Please join us on

Friday, April 15, 2016 at 6:30 at

KIDTOWN USA

1071 S. Roselle Rd. Schaumburg, IL

RSVP at

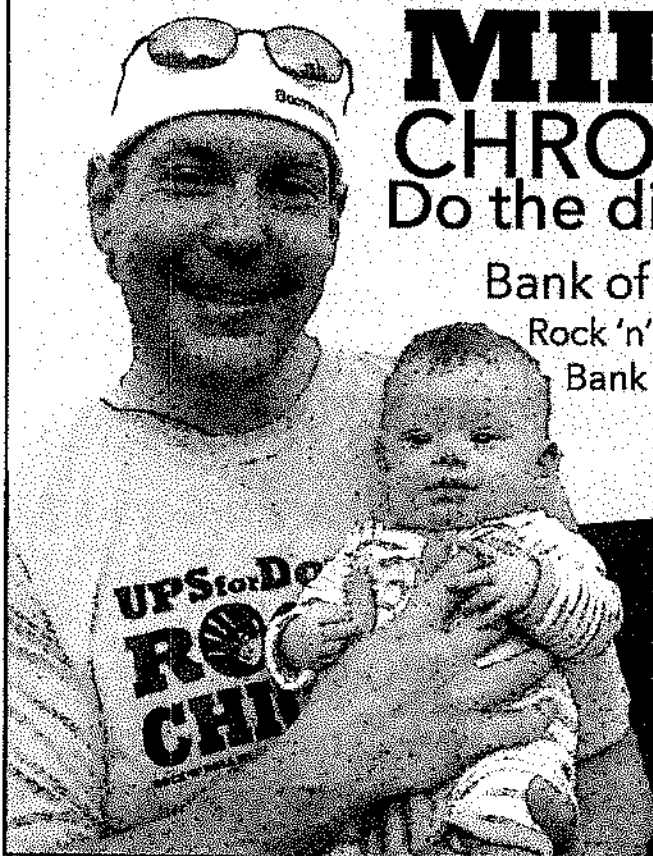
www.familyfriday.eventbrite.com

For questions, please contact Jessica Rathman at jessicarathman@gmail.com

MILES COUNT. CHROMOSOMES DON'T. Do the distance for Down syndrome.

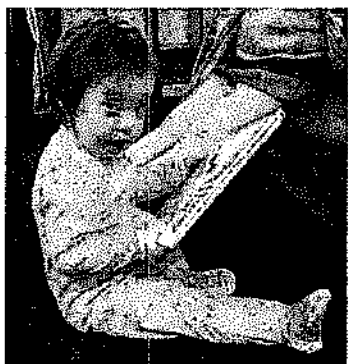
Bank of America Chicago Marathon
 Rock 'n' Roll Chicago Half Marathon & 10K
 Bank of America Shamrock Shuffle 8K
 Schaumburg Shuffle 5K

marathon@upsfordowns.org



upsfordowns.org

**UPS FOR DownS
 RUNS
 CHICAGO** 




Penny knows how to party! Family Friday is where it's at!



Know Your Options under Ligas Consent Decree

Kimberly Johnson-Evans is a parent of a son with Autism and has been involved in the ARC of IL, the Chicagoland Autism Connection, and is a Ligas Family Advocate.

Adulthood is the longest period of our children's lives. Professionals, parents and guardians need to work together and be educated on the issues.

Stanley Ligas Lawsuit – Stanley was living in an intermediate care facility and wanted to live in the community, play his music, and pick his own roommate. In the facility, he was told his schedule and had no individual choices. His family filed a lawsuit, and six years later they won, which resulted in the Ligas Consent Decree. This is now part of the budget stalemate – Illinois had no plan for moving people into community living. Illinois said it would be 

ADULT HOUSING OPTIONS: A MULTI-PART SERIES

Tuesday, April 5, 2016
7:00 - 9:00 p.m.

WHY CAN'T I JUST LIVE IN MY OWN APARTMENT?

Explore what changes need to occur to create flexibility with housing and day-to-day activities & opportunities

John Fallon, Senior Program Manager for supportive housing with CSH

Tuesday, May 3, 2016
7:00 - 9:00 p.m.

DO IT YOURSELF HOUSING

A practical approach to supportive housing and living an inclusive life in your community. Will provide specific examples for individuals who do not have state housing funding.

Teri Steinberg, disability consultant and frequent lecturer and trainer.

All are welcome.

Sign up for BOTH dates and get more information:

www.adultissueshousing.eventbrite.com



➡ done in the future. The current governor is saying Illinois doesn't need a court order and should not have to follow the decree.

PUNS stands for the Prioritization and Urgency of Needs and Services. There are 23,000 people on the PUNS list in Illinois. Most people who are placed in housing in Illinois are in the old system, with very few exceptions. UCP does a report of the states, and Illinois is 49th on the report list for community services.

The new Ligas court monitor is Ronnie Cohn, who determined that Illinois is not in compliance with the consent decree (which is being implemented within the Illinois Department of Human Services)

There are eighteen Independent Service Coordination Agencies (ISC) in Illinois. For the northwest suburbs, you would update/sign up for PUNS with Community Alternatives (CAU). There are a staggering number of acronyms parents to become familiar with. Johnson-Evans suggested that everyone keep a folder containing: acronym list, son/daughter's most important information, psychological evaluation (this is important, because if your child is selected, he/she needs to have a recent [≤ 5 years] psychological evaluation [IQ test]).

PUNS selections occur occasionally, and those selected receive a letter to get prequalified for services. If you get this letter, the clock starts ticking, so learn your options. First, choose a provider agency (see handout: Selecting a Provider Agency - <http://www.ligasfamilyadvocateprogram.org/wp-content/uploads/2014/09/Selecting-A-Provider-Agency1.pdf>).

If you do receive an award letter, it may be for only CILA, or only Home Based Services, OR BOTH options, which means you have to



choose one. CILA is the group home option with supports provided by the provider. Home Based Services allows for more flexibility and self-direction with personal support workers for shopping, cleaning, jobs, transportation, etc.

Be sure to renew PUNS yearly. Express your child's needs honestly, from the perspective of your worst day, not your best day - because higher needs put you in the more urgent category. Services are expedited if an emergency exists.

How do we change this dismal situation? We need to make a collective difference. Stay on top of legislative issues. Contact your state reps frequently. Introduce yourself as a constituent and make sure they know you and know your family - you don't need to ask for anything. Just make the connection. These relationships provide you with more credibility, confidence and access when something important arises.

Johnson-Evans showed a video by CQL - available online <http://www.c-q-l.org/ligas-outreach>

- JOIN this free egroup: Illinois Parents of Adults with Developmental Disabilities: www.groups.yahoo.com/IPADDUnite
- www.thearcofil.org
- www.disabilitycoop.org
- www.ligasfamilyadvocateprogram.org

Celiac and Down syndrome

On March 15, Dr. Hilary Jericho, Director of Pediatric Research at the Celiac Center of the University of Chicago, gave a presentation entitled "Celiac disease and Down syndrome". Celiac disease is a condition where the body is unable to properly digest barley, rye, and wheat products, causing damage to the lining of the intestine and preventing the absorption of certain nutrients. As the condition can range from mild to

severe, the symptoms can also vary. Possible symptoms include difficulty gaining weight, diarrhea, vomiting, constipation, nutritional deficiencies and general irritability or behavior changes. An initial diagnosis can be made through a simple blood test, but a definitive test requires a special procedure from a GI specialist.

There is a higher rate of this condition in individuals with Down syndrome; up to 16% of individuals with Ds are believed to have Celiac disease. Because of this high percentage, all children with Ds between the ages of 2 and 3 should be screened for Celiac disease with the simple blood test. In addition, doctors should consider screening tests for adults with Ds, especially when there is weight loss, poor nutrition or persistent changes in bowel habits. Left untreated, Celiac disease can result in malnutrition, decreased growth, and, in rare cases, intestinal cancer (lymphoma). The treatment is dietary and involves eliminating all barley, rye and wheat from the diet--eliminating gluten.

The small bowel has many roles, one of which is to absorb nutrients from our food. Celiac disease arises when the lining of the small bowel becomes damaged from exposure to gluten, the protein found in barley, rye, and wheat. Oats may be involved because oats are often contaminated with gluten from other grains during the milling process. The small bowel becomes unable to absorb water

and nutrients, causing a number of different symptoms.

Why does a child get Celiac disease? First, the disease arises only after exposure to gluten.

Second, there is usually a genetic predisposition toward a "sensitive" small bowel lining. Third, a certain environmental irritation may make the lining more susceptible to injury from gluten, such as gastrointestinal surgery or a gastrointestinal infection. The gluten causes an immunologic response in the lining of the small bowel, and the surface folds of the intestine shrink and flatten and a "malabsorption" condition occurs.

Studies in the 1990s indicated that children with Ds are at a higher risk to develop Celiac disease than the general population. The reasons for that aren't entirely clear, but since children with Ds are at greater risk from auto-immune diseases, and Celiac disease represents another one of these types of diseases, this may be the reason. The



➔ signs of Celiac disease are varied, since the condition may be very mild in some cases and severe in others. The majority of children with Celiac disease have what doctors may term "failure to thrive", a lack of growth of weight and height. Most have diarrhea and/or vomiting. Many children with Celiac disease are irritable and usually have a decreased appetite. The stools may be foul smelling, and for some, may not be loose but big and bulky. Children who have had Celiac disease for several months will have bloated stomachs and a loss of muscle mass. If not treated, the inability of the small intestine to absorb water and nutrients will cause undernourishment, producing anemia, osteoporosis and peripheral neuropathy. Children with Ds who develop Celiac disease may actually have few symptoms at all, leading to what is called "silent" Celiac disease.

The main way of diagnosing Celiac disease has always been through a biopsy of the small bowel. Under a microscope, the small bowel will show characteristic damage to the lining. Since a small bowel biopsy is neither easy nor cheap, it's not in the best interest of the child to do a biopsy on every child with Ds. So the best solution would be to have the easy blood test that can detect the children who need the diagnostic biopsy. A few blood tests have been tried in the past with unhelpful results, such as the antigliadin antibody (AGA) test, which is not used currently. Another test looks for antiendomysium antibodies (EMA). However, the interpretation of this test is operator-dependent and prone to errors. The

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.

current test looks for IgA antibodies to the enzyme transglutaminase (TG). TG is an intracellular enzyme that binds gliadin and starts to process it in a way that starts the autoimmune sequence in Celiac disease. As the TG test has turned out to be a very sensitive and specific screening test for Celiac disease, it has become the favored screening test, especially for children and adults who have no symptoms of Celiac disease. It should be noted that all these tests are measuring IgA levels of the antibodies. One problem is that IgA deficiency may occur in people with Celiac disease, and therefore the IgA markers for Celiac disease may not show up. That would be called a "false positive". For that reason, every time a person has a blood test for Celiac disease, the doctor should also test for total IgA levels. Screening for Celiac disease in children with Ds is still controversial, as some doctors do not believe it occurs often enough to be cost effective, and other doctors feel that all children with Ds need to be screened are unsure about the best age, or even if one screen is enough.

Recent research has found that 97 to 98% of all cases of Celiac disease are found in people with certain markers called HLA (human leukocyte antigen) markers. There are two markers that are associated with Celiac disease: HLA-DQ2 and HLA-DQ8. In cases where Celiac is suspected and there is an IgA deficiency, these markers are looked for instead to determine if a small bowel biopsy is warranted. Interestingly, the genes for HLA markers are on the chromosome 6, so the connection to chromosome 21 is still being researched. In one study, nearly 100% of children with Ds and celiac disease had the HLA DQ2 marker, which suggests that the genetic influence from having the extra chromosome 21, in combination with a specific gene variation on at least one other chromosome, leads to the development of Celiac disease. For more information, you may contact Dr. Jericho at the Celiac Center, at the University of Chicago.

UPS for Downs Theatre Company presents:



7PM THURSDAY APRIL 14th*
7PM FRIDAY APRIL 15th*
7PM SATURDAY APRIL 16th*
2PM SUNDAY APRIL 17th*

Community-based musical theatre for people with Down syndrome, friends, peers... and you! Come play with us!

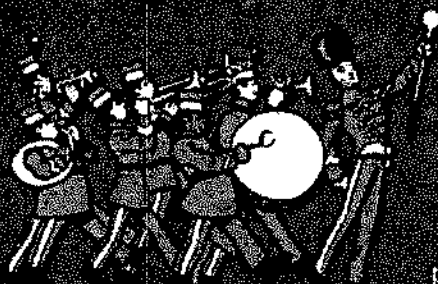
Performed at:
Ridgewood High School
Norridge, Illinois

PRESALE online: \$11
ALL SHOW PASS: \$30
AT THE DOOR: \$15

Directed by EDGE Theatre

GET YOUR TICKETS AT:

www.ufdmusicman.eventbrite.com



Questions? Call 847-895-2100 or e-mail spazerunas@upsfordowns.org

*Show leads are double cast. If you are coming to see specific performers in lead roles, check ticket details carefully before purchasing.

MAY MEETING

Invite your parents and siblings to this unique meeting to get their questions about Down syndrome answered

Tuesday, May 17th
7:30 p.m.

Fox Run Golf Links Clubhouse,

RSVP and get more information at:

www.ExtendedFamily.eventbrite.com

UPS FOR Downs ROCKS CHICAGO

JOIN OUR TEAM FOR
THE ROCK 'N' ROLL CHICAGO
HALF MARATHON & 10K

Sunday, July 17, 2016

Fundraising expectation is just \$250 per runner.
Recruit friends & family and sign up today!

www.ufdrockschicago.eventbrite.com



AGES 9-12

BUBBLE SOCCER is played much like classic soccer, on the same field, all while wearing a "bubble".

When: **Saturday, April 23 at 10:00 a.m.**

Where: Schaumburg Park District Sport Center

What: 1 hour of Bubble Soccer (indoor soccer field) and 1 hour for pizza/beverages

Cost: \$10 per participant



Please join us! Invite a friend, neighbor or classmate age 9 - 12 with or without Down syndrome to participate for a fun and hilarious event. RSVP by April 16 to Shawna Lochner at slochner@upsfordowns.org



AGES 13-16



Lanes & Lounge

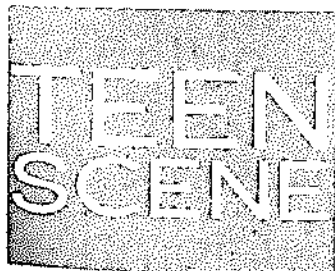
This month UPS for DownS is hosting its next Early Teen Social Club at Strike Ten!

Who: Any neighbor, classmate, cousin, sibling or friend with or without Down syndrome age 13 - 16 years old is invited to participate in this fun monthly program.

When: **Sunday, April 24 at 2:00 p.m.**

Where: Strike Ten Bowl 800 E. Nerge Rd, Roselle

RSVP: by April 17 to Heather Vargas at hvargas@upsfordowns.org



AGES 16-20

WHO: This is an integrated social event for anyone between the ages of 16 and 20 years old. We encourage you to reach out to friends, family, and classmates.

DATE: **Saturday, April 23, 2016**

WHAT: Pinstripes in Oak Brook

TIME: 7:00 p.m. - 9:00 p.m.

COST: \$5 per person. UFD subsidizes the rest!

RSVP at <http://teenscene-April2016.eventbrite.com>



Questions? Contact Gloria Nolan at 847-347-6127 or gnolan738@yahoo.com

PARENT NIGHT OUT



Date: Saturday, April 9
Time: 8:00 p.m. seating
What: Argentinean restaurant
Where: Artistic Cuisine
 16 S. Bothwell
 Palatine, IL
Cost: \$20 per person
 UFD covers the rest

Includes: 4 course dinner

**RSVP TO STEPHANIE AT
 SNERI@UPSFORDOWNS.ORG**

PARENT COFFEE & PLAYGROUP

ALL AGES WELCOME!

NOON - 1:30 p.m.

Tuesday, April 5, 2016

Friday, May 13, 2016

First United Methodist Church
 1903 E. Euclid Avenue, Arlington Heights
 Child care and a light lunch will be provided - courtesy of UPS for Downs.

Questions? Contact Shannon at
 847-894-8782 or skersemeier@gmail.com

2016 CONTACT INFORMATION

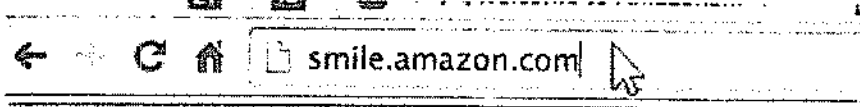
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New Parent Coordinator	Shannon Kersemeier	847-788-1138	skersemeier@gmail.com
Family Friday	Jessica Rathman	630-536-6739	jrathman@gmail.com
Dinner Dance	Stephanie Neri	847-891-3224	sneri@upsfordowns.org
TeenScene	Kim Orlando	630-404-5312	korlando@upsfordowns.org
Adult Social Group	Margaret Gawlik	847-895-2100	adultsocialclub@upsfordowns.org
Office Manager	Anita Herr	847-895-2100	office@upsfordowns.org
Theatre Programming	Sandy Pazerunas	847-705-0715	spazerunas@upsfordowns.org
Endurance Team	Terri Devine	708-341-1046	marathon@upsfordowns.org

amazon smile

You shop. Amazon gives.

Are you a fan of Amazon? Do you like shopping? If you currently order from Amazon or if you are thinking about buying gifts or items online, think AmazonSmile! AmazonSmile is a simple and automatic way for you to support your favorite charitable organization every time you shop, at no cost to you. They will donate a portion of the purchase price to UPS for Downs. All you have to do is sign up or find AmazonSmile and select UPS for Downs as your charitable organization!

1. Visit smile.amazon.com.



2. Sign in and Choose Your Charity
- search for UPS for Downs
3. Begin shopping.
4. Share with your friends!



UPS for Downs would like to give a special thank you to our friend Chuck Villano. Chuck has been supporting UPS for Downs for years. He has been involved with our organization for several years. Recently, he hosted an event at the Lake Zurich Theater where attendees were encouraged to donate to UPS for Downs. The event was a success! The theater was packed and he helped us raise several hundred dollars! UPS for Downs... Zootopia... popcorn... what more could we ask for!? Thanks Chuck!



Advocacy Day Wednesday May 11, 2016

 **equality
opportunity**
improved
quality of life.

Illinois State Capitol Rotunda Springfield, Illinois

Speak up and speak out to
show support for people
with disabilities living in the
community.

Going Home is an advocacy
campaign dedicated to full
inclusion and equality for
people with intellectual and
developmental disabilities.

For more information call
618-806-9431 or go to
www.goinghomeillinois.org

**Let's work together
for equality for
people with
disabilities!**



UPS for Downs

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847 *****AUTO**3-DIGIT 601 T5 P1

Amy Longmore
Hoffman Estates High School
1100 W Higgins Rd
Hoffman Estates, IL 60169-4050

LUKE ROBERT

Nickname: Lukey

DATE OF BIRTH: January 9, 2014

OCCUPATION:

Reading books and pushing out poop!

LAST BOOK READ: Baby Shoes by Dashka Slater

HOBBY: Getting into the pantry and taking out my own snacks!

FAVORITE FOOD: Taquitos and Gluten-Free Chicken Nuggets

FAVORITE MOVIE: Anything Sesame Street

FAVORITE THING ABOUT PRESCHOOL: Circle Time

LATEST ACCOMPLISHMENT: Opening the door

JOKE: Knock Knock. Who's there? Interrupting cow. Interrupting cow wh... Moo!

