



UPSforDownS

United Parent Support for Down Syndrome
Support • Information • Community

January 2017

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Note from the Board.

UPS for Downs started over thirty years ago as a support group for families with children with Down syndrome. It has grown to include the mission of support, information, and community inclusion and belonging. Our programs support our mission.

UPS for Downs is an organization for all persons with Down syndrome and their families. Community belonging and living integrated and inclusive lives are fundamental to our mission. Equally important are the two other key components of our mission: support and information.

As we move into 2017, UPS for Downs welcomes new faces to the board and sends our deep gratitude and thanks to departing board members. Please join us in welcoming to the board Samantha Shimanek and Dave Wilkinson.

Sam is a sibling who has grown up with UPS for Downs, participating in Sibshops and our organization's family activities for her entire life. Sam is a leader with our theatre program and leads Sibshops for our youth. In her spare time, she makes a living as a teacher! ➡



The 21st Annual Holiday Party saw Santa busting a move on the dance floor - and he brought personally selected gifts for all the kids!

Orthotics & Down syndrome

Tuesday, January 17 at 7:30 p.m.
Fox Run Golf Links Clubhouse in Elk Grove

Does your child wear orthotics, or has a doctor or therapist suggested them? Orthotics are often prescribed to correct and support the joints in children with DS. Learn from experts from Scheck & Siress about when, why, and how long orthotics may be helpful for your child.

Get details and register for FREE:

www.ufdORTHOTICS.eventbrite.com

At a glance...

Saturday, January 7, 2017
Family Winter Swim Party

Saturday, January 14, 2017
Parent Night Out Trivia

Tuesday, January 17, 2017
Orthotics & Down syndrome

Friday, January 20, 2017
Family Friday

Saturday, January 21, 2017
Adult Social Club Laser Tag
Teen Scene Dance

Thursday, January 26, 2017
Adult Matters: Employment

Friday, February 7, 2017
Parent Coffee & Playgroup

Saturday, February 11, 2017
kiDs Club: Rock Climbing

Thursdays, February 16, 2017
thru May 11, 2017
Healthy Eating

Friday, February 17, 2017
Family Friday

Tuesday, February 21, 2017
Marriage & Family Relationships



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



Dave Wilkinson is the father of Brett and Brooke, who both attend Buffalo Grove High School. With support, education, and encouragement, Dave and his wife Sandy have pushed boundaries and found that Brett continues to rise to every challenge. Having been on the receiving end of so much assistance, Dave is excited to give back and increase his commitment to the organization.



Sam Shimanek

Shawna Lochner, Vicki Kirkpatrick and Laura Fogarty have opted to conclude their board service. We thank Laura for her insight as a sibling and her expertise as an educator. As passionate advocates and parents of now school-age children, Shawna and Vicki have strengthened the community component of our mission and they have both been invaluable in creating programs that reach out to young families and foster a firm belief in the mission of community inclusion and high expectations. We look forward to continuing to work together in a variety of ways.



Dave Wilkinson

There are loads of opportunities for you to volunteer your time in many ways, both large and small. **We have a pressing need for NEW LEADERSHIP for our Dinner Dance event.** If you are organized and love to plan one of a kind events that truly puts the FUN in fundraising, please contact us at BoD@upsfordowns.org

We expect to expand the board further in 2017. Board members attend meetings at the UPS for DownS office monthly, provide oversight and strategic planning for the organization. Board members also serve on event and program committees. If you have a sense of purpose, vision, time to commit, and would like to learn more, please email the Board of Directors at BoD@upsfordowns.org

Thank you!

IQ Testing and Down syndrome

On November 15, 2016, Special Education Directors from District 54 presented information regarding IQ testing: Why should we consider this? IQ testing for individuals with Down syndrome seems to always serve as another reminder that trisomy 21 will define the individual and prove that the individual is always behind in some measure. However, there are several very important purposes for testing students with Down syndrome, especially those students who are transition-aged, 18-22. They are to determine: eligibility for services, level of services needed, career interests and abilities, and readiness for postsecondary education or college.

As your child prepares to leave the school system, the state adult service agency will, in most instances, require that the individual undergo eligibility determination to see whether he or she qualifies for adult services. These services can include residential supports, employment supports, transportation, day programs, and service coordination. Even if your child received services as a child, from the very same agency (the Department of Developmental Disabilities, for example), he or she will most likely be required to undergo eligibility determination again. For families of children with Down syndrome, this seems a little ridiculous. The extra chromosome is still there, the person still has Down syndrome, and many of you are thinking, "Why can't this be enough?"

The reality is that each state has criteria to determine eligibility. While some states determine eligibility once, usually when the

individual first requests services, many use different eligibility criteria for children than for adults. Some states are more lenient in determining childhood disability than they are for determining adult disability. This is due to the wider eligibility for services under IDEA.

The other reality is that some students make enough gains and progress in school that they no longer need services as adults. This is the basic premise for providing special education in the first place—so students receive the help needed to master the skills necessary to be successful as adults.

Since there are no separate eligibility criteria for individuals with Down syndrome, you can expect that your child will undergo an eligibility determination for adult services.

You should inquire with the appropriate state agency or with your school district as to the age this occurs. Test results from when your child was younger will not be considered in most situations, so don't bother getting your child tested at the earliest possible age in hopes you will somehow minimize the waiting for adult eligibility.

Although the overwhelming majority of people with Down syndrome will qualify for adult services, some of the most "high functioning" of our children may not be eligible. Eligibility usually is based on three factors:

1. Some states quantify it with an actual IQ score (usually below the 68-70 range), and other states use an "IQ  score that is two standard





deviations below the norm." Since the norm is 100, both definitions mean much the same.

2. The limitations in intellectual functioning must be accompanied by significant limitations in adaptive functioning in at least two of the following skill areas:
 - a. communication,
 - b. self-direction,
 - c. functional academic skills,
 - d. work,
 - e. leisure,
 - f. health, and
 - g. safety.
3. The onset must have occurred before the individual's 22nd birthday.

This is meant as a general guide.

To qualify for adult services, an adult with Down syndrome generally needs to meet the criteria for intellectual disabilities (mental retardation), or whatever term is being used to refer to people whose cognitive limitations result in a score that is generally 70 or below. Some people with Down syndrome might also qualify for services from the state agency that supports people who are deaf, hard of hearing, or blind. However, the agency that supports individuals with intellectual disabilities generally has the expertise, service models, and resources to best assist people with Down syndrome.

There are various assessment tools used to measure cognitive intelligence. Among them are: I Wechsler Intelligence Scale for Children - Fourth Edition (WISC-IV) I Wechsler Adult Intelligence Scale—Fourth Edition (WAIS-IV) I Stanford-Binet Intelligence Scales—Fifth Edition (SBS) I Kaufman Assessment Battery for Children—Second Edition (KABC-2) I Woodcock-Johnson III Tests of Cognitive Abilities (WJ-III) I Differential Abilities Scale (DAS) I Naglieri Test of Nonverbal Intelligence I Comprehensive Test of Nonverbal Intelligence (C-TONI). Standard IQ tests measure verbal skills (such as the ability to

define words or explain how two or more concepts are similar), nonverbal skills (such as the ability to copy patterns or predict what shape comes next in a sequence), short-term memory (such as the ability to repeat back a string of numbers, either forward or backwards), and processing speed (such as the ability to look at shapes that are keyed to numbers and write down the corresponding number).

Most parents of children with Down syndrome believe that traditional intelligence tests have marginal use in their children's lives. Our children perform better than their test scores indicate, and the tests fail to capture their special talents. Low scores on IQ tests can also demonstrate lack of access to the education that typical children receive.

Currently, there is no getting around IQ scores to determine eligibility for some services and benefits—just like there is no way around some kind of measure for college admissions, be it grades, test scores, or some combination of both.

During the transition years, IQ testing can be used for two very different purposes: 1) as part of the admission process for a postsecondary program, and 2) as part of the determination process to qualify for Supplemental Security Income (SSI).

Many parents prevent the school from doing IQ testing on their child, if at all possible, for fear that a low test score may lead to lowered expectations or fewer opportunities for inclusion. This is a personal decision. But as your child approaches the end of her high school career, it may be wise to consider IQ testing. If you don't have it done by the school, you will need to pay someone privately to do it to qualify your child for SSI and adult services. This can cost several thousands of dollars. While some of the expense may be covered by insurance, it can be expensive.



SATURDAY, JANUARY 7
6 - 9 p.m.

2017 Winter Swim Party

Schaumburg Waterworks Indoor Water Park

<http://winterswimparty.eventbrite.com>



AGES 9-12



Rock Climbing!

WHO: kiDs Social Club (9-12)

WHERE: LifeTime Fitness in Schaumburg

DATE: Saturday, February 11, 2017

TIME: TBA - contact Shawna for details

KiDs will participate in guided rock climbing for an hour followed by a light snack. All neighbors, siblings, classmates and friends between the ages 9 - 12 with or without Down syndrome are invited and encouraged to attend.

To register, e-mail Shawna at slochner@upsfordowns.org by November 8. REGISTER EARLY • LIMITED CAPACITY.



AGES 21&UP

Come blow away winter with Adult Social Club!

WHO: Anyone over 21. No parents, please.

WHEN: Saturday, January 21, 2017

WHAT: Tactical Laser Tag

WHERE: Battle House Laser Combat

COST: \$10 per person (UFD pays the rest)

RSVP: adultsocialclub@upsfordowns.org

Questions: Email adultsocialclub@upsfordowns.org



The logo for TEEN SCENE, featuring the words "TEEN" and "SCENE" stacked vertically in white, bold, sans-serif capital letters on a blue rectangular background.

WINTER DANCE PARTY: BRING A FRIEND

DANCE WITH DJ AND LIGHT SNACKS

WHO: All teens and same age siblings and friends;
co-hosted with the Holy Ghost Church Teen Spirit Group

WHERE: Holy Ghost Catholic Church gymnasium,
254 Wood Dale Road, Wood Dale, IL 60191

WHEN: 7:00 p.m. - 9:00 p.m. on **Saturday, January 21, 2017**

COST: \$5 collected at the door

RSVP at <http://teenscene-winterdance-2017.eventbrite.com>

DRESS CODE: Dance attire preferable; no sweats or t-shirts!

Questions? contact Patricia Shimanek at 630-605-3807 or
pshimanek@hotmail.com.

ADULT MATTERS: EMPLOYMENT SERIES

Thursday, January 26, 2017

7:00 - 9:00 p.m.

Fox Run Golf Links, 333 Plum Grove Road, Elk Grove Village

Teaching Together Chicago has a mission to expand paid employment opportunities for adults with disabilities in Catholic Schools through paid internships that include clerical, classroom assistance, maintenance, or extracurricular programs. Internships are typically 16 hours per weeks for 10 weeks.

Brookfield Zoo Project SEARCH is a collaborative-partnership job training model that centers around a unique, business-led, one-year program taking place entirely at the workplace.

The Empower Program is starting in February, 2017 which provides confidence and skills to individuals with disabilities. The program is meant to serve as an intermediary step for those interested in employment or other community opportunities but may not be ready for a traditional vocational program.

All are welcome.

Sign up and get more information:

www.EmploymentSeries.eventbrite.com



21st ANNUAL HOLIDAY PARTY

Thank you for another fun-filled UPS for DownS Holiday Party! The wintry day saw more than 250 guests come out to see Santa and enjoy friends and good food. A HUGE thank you to all of our volunteers who shopped, wrapped, decorated and assisted the day of the party. This event would not be a success without you. Happy New Year to All!

KRISTYNN BRIGGS



Happy New Year!

Time to make healthy resolutions!



This new UPS for DownS program is offered to adults who are looking for guidance and easy to implement steps to improve health

and fitness. Though designed with adults with Down syndrome in mind, the program is perfect for anyone seeking an easy to follow, goal-oriented journey to better healthy living. Leading the program are three dietitians/personal trainers: Susan Rizzo, Kathy Stanislawski and Kim Jurkowski.

Location: Prince of Peace United Methodist Church, 1400 S. Arlington Heights Road, Elk Grove Village

Dates: 12 Thursdays from February 16 to May 11, 2017

Time: 6:30 – 7:30 PM

Cost: \$60 for the 12 week program (only \$5 per week)!

REGISTER TODAY!

ufdhealthyeating.eventbrite.com

Questions? Contact Pat Fogarty at
pfogarty@upsfordowns.org

PARENT NIGHT OUT

TRIVIA NIGHT



Date: Saturday, January 14

Time: 7:30 p.m.

What: Dinner & Trivia to follow

Where: *Tony Spavone's
Ristorante*

206 W. LAKE STREET, BLOOMINGDALE, IL

Cost: \$20 per person

UPS for DownS covers the balance

RSVP TO STEPHANIE AT
SNERI@UPSFORDOWNS.ORG

ENDURANCE ATHLETES COME IN ALL SHAPES AND SIZES, including yours! Make it happen in 2017.

We have races for all fitness levels and abilities.

April 2: Shamrock Shuffle 8K

July 16: Rock 'n' Roll Chicago Half Marathon & 10K

August: Chicago Super Run 5K

October 7: Bank of America Chicago Marathon

Contact us at
marathon@upsfordowns.org

Down Syndrome Research Study

Research study title: Effects of Aerobic Exercise on Cerebral Blood Flow and Cognitive Function in Individuals with Down Syndrome

- Do you or one of your family members have **Down Syndrome**?
- Are you between the ages of 18-40?
- Do you want to find out more about if exercise can improve cognitive function of individuals with **Down Syndrome**?

We are conducting a research study with individuals with **Down Syndrome** in brain blood flow & cognitive function responses to exercise

The study will include:

1. Cardiorespiratory fitness assessment
2. Heart rate and Blood pressure response
3. Measurements of brain blood flow and cognitive function



This study is being conducted by Sang Ouk Wee (Tommy) in Rehabilitation Science at UIC.
The study will take place in our lab at 1640 W. Roosevelt Rd.

Please contact **Sang Ouk Wee** if interested!
312-996-9607 or swee3@uic.edu

The Integrative Physiology Laboratory at the University of Illinois at Chicago is looking for participants for an exercise and cognitive function research study in individuals with Down syndrome. We are looking for healthy individuals with and without Down syndrome between 18 and 40 years of age. We are interested in investigating how exercise may improve cognitive function related to brain blood flow. The study includes fitness and cardiovascular health testing including arterial health and aerobic capacity. Participants will receive monetary compensation upon completion of the study.

2016 CONTACT INFORMATION

Calendars	Shannon Denna	847-895-2100	calendar@upsfordowns.org
kiDs Social Club	Shawna Lochner	224-343-2898	slochner@upsfordowns.org
Program Committee	Erin Gunsteen	847-895-2100	eringunsteen@gmail.com
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	skersemeier@gmail.com
Family Friday	Jessica Rathman	630-536-6739	jessicarathman@gmail.com
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

FEBRUARY MEETING MARRIAGE & THE FAMILY

Tuesday, February 21st at 7:30 p.m.

Fox Run Golf Links Clubhouse,
333 Plum Grove Road; Elk Grove Village

We invite you and your spouse to join us in an informative perspective on marriage, relationships, and how your relationship is the glue that keeps the family together, even in the most stressful times.

RSVP and get more information at:
www.MarriageFamily.eventbrite.com

2017 UPS for DownS CALENDARS AVAILABLE!

Mail your check payable to UPS for DownS or credit card info (including exp/sec code/zip) to:

Calendar/UPS for DownS
1070 S. Roselle Road
Schaumburg, IL 60193

Include your mailing address, phone number and email address.

Calendars are available by mail for \$15 each (includes shipping) or at a discounted price of \$10 if purchased at an UFD event or picked up from the office. Bulk mail orders of 5 or more can receive a discounted shipping rate.

QUESTIONS?

Contact calendar@upsfordowns.org



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, January 20, 2017

Friday, February 17, 2017

at 6:30 at

KIDTOWN USA

1071 S. Roselle Rd. Schaumburg, IL

PARENT COFFEE & PLAYGROUP

ALL AGES WELCOME!

NOON - 1:30 p.m.

Tuesday, February 7

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

Light lunch & child care provided.

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



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1070 S. Roselle Road
Schaumburg, IL 60193

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



CHLOE HOPE
Nickname: Chlo Chlo, Stinkpot,
Munchkin, Troublemaker

DATE OF BIRTH: June 20, 2012

OCCUPATION: Director of
Operation Brighten Every Room I Walk Into

LAST BOOK READ:
Flat Stanley and the Really Big Cookie

**FAVORITE THING
ABOUT SCHOOL:**
Socializing

HOBBY:
Dancing, trampoline jumping

FAVORITE FOOD:
Hot Cereal and Pancakes

FAVORITE MOVIE:
The Wizard of Oz

LATEST ACCOMPLISHMENT:
Fully potty-trained, nighttime included

QUOTE: "Thank you!" and
telling others to "Eat, Eat" at mealtime