



# UPS for Downs

United Parent Support for Down Syndrome  
Support • Information • Community

**March/April 2018**

## In this Issue

Note from the Board. ....1  
 Friendships & Ds .....1  
 At a Glance .....2  
 Managing Stress .....3-4  
 Patrick Schwarz.....3  
 Maine West.....4  
 Junior Teen Social Club.....5  
 Oz for All .....5-8  
 Theatre Classes .....7  
 Family Friday.....8  
 Family Retreat .....8  
 Parent Night Out .....9  
 Recognition Certificates .....9  
 Sensory Processing .....10  
 Social Media .....10  
 Commitment to Excellence 11  
 Scholarships.....Back Page

## Note from the Board.

Dear UPS for Downs families:

My name is Besset Sabourin and I am a new UFD board member. I am honored to join an organization that is driven by parents and that has done so much for individuals with Ds and their families. I have been in the special education field for over 10 years. My wife, Jenny, and I have two children. Ellie is three years old and has Down syndrome. Charlie is 7 months old and adores his sister.

Just over 3 years ago, a message was posted on social media from an adoption agency looking for potential parents for a newborn baby girl with Ds. My wife and I responded with our interest (on a whim) and we immediately began the adoption process. We were hoping to start a family soon, so we were overjoyed when Ellie joined our family, just two short months after the online posting.

Disability issues have always been important to me. I went into special education because I did not believe that students who learn differently, like my brother, had the same access and opportunities as their peers. My dream has been to create



*Sam McLeod enjoyed his first show with the UPS for Downs Theatre Company.*

## Friendships & Ds

Tuesday, March 20 at 7:30 p.m.  
 Fox Run Golf Links Clubhouse  
 333 Plum Grove Road, Elk Grove Village

Inclusion advocates Bridget and Nancy Brown will share pathways and a variety of methods of creating and maintaining friendships.

Get details and register for FREE:  
[www.ufdFriendships.eventbrite.com](http://www.ufdFriendships.eventbrite.com)

## At a glance...

Friday, March 16, 2018  
Family Friday

Saturday, March 17, 2018  
Senior Teens @ Windy City Bulls

Tuesday, March 20, 2018  
Friendships & Down syndrome

Saturday, March 24, 2018  
Parent Night Out: Laugh Out Loud

Sunday, April 1, 2018  
Scholarship application deadline

Tuesday, April 3, 2018  
Theatre classes begin

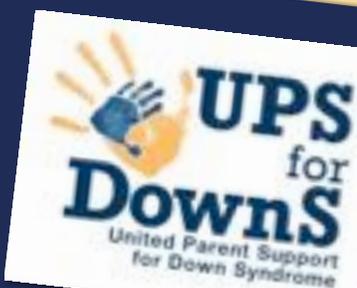
Saturday, April 14, 2018  
Junior Teen Soccer Clinic  
Daddy/Daughter Dance (ages 3-11)  
Maine West High School

Sunday, April 15, 2018  
Commitment to Excellence deadline

Tuesday, April 17, 2018  
Curricular Modification  
with Patrick Schwarz

Friday, April 20, 2018  
Family Friday

Saturday, April 21, 2018  
Parent Night Out: Melting Pot



1070 S. Roselle Road  
Schaumburg, IL 60193  
[www.upsfordowns.org](http://www.upsfordowns.org)



inclusive schools and communities in which each person is able to bring their uniqueness to the table. I believe we all have talents and we need to help each child realize and share those gifts within their schools and communities.



Over ten years ago, I started my education career in transition programming, teaching students ages 18 to 21. I then became a middle school special education team leader, and now I am a district director of student services. I also have experience working in adult day programming and special recreation. I have seen kids do amazing things when adults have high expectations and give them space to grow and be themselves.

As a special education professional, I thought I knew what it would be like to raise a child with Ds. We sure have learned a lot from the Ellie and other parents with children with Ds. Through early intervention and now in preschool, I have experienced the full spectrum of being a dad of a daughter with Down syndrome. UPS for DownS has provided my family with opportunities to learn about important issues, meet other parents, and see others with Ds shine on stage. Ellie even had an opportunity to be in the calendar.

We must build upon the successes of the UPS for DownS families who have paved the way. In my effort to become a better dad and advocate for others, I will continue learning from you and other UFD families. Along with Bill Weldon, I am coordinating the monthly informational meetings nights and I hope you can stop by to hear some great speakers and meet other parents. If you have any ideas for future speakers or topics you'd like to hear about, please feel free to contact me at [bsabourin@upsfordowns.org](mailto:bsabourin@upsfordowns.org).

Thank you,

BTSL

# Managing Parental Stress

On January 16, Diane Gould, LCSW,BCBA, presented "Managing Parental Stress".

Many of us spend our days managing everyone else, the kids, work situations, household issues, and more, and we neglect to give ourselves permission to "let go". We need to be able to put our "burdens" down. For example, if you were to consider the weight of a glass of water, the weight would be considered minimal, and you might not consider it a burden to hold it; however, if you had to hold that glass of water for an hour, six hours or a day, the burden would feel increasingly heavy, and you wouldn't be able to hold or carry it. The same concept applies for the daily stressors we face as parents. Often we feel we must take care of everyone else, before we can stop and take care of ourselves. You might feel that this is part of life, and it is, but you must consider the feelings the stress can cause. Anything that causes a change in your body is a stressor, and the stressors can be good and bad. Stress often motivates people to make necessary and healthy life changes. The key is to know yourself,

recognize that you feel the stress, since stressors are different for different people.

The effects of stress can create havoc in the body if a person does not recognize that they feel stressed. The body will recognize the stress, and it will react to the stress, whether or not the mind recognizes or acknowledges the stress. An estimated **60-90% of doctor visits are stress related**, which includes ER visits. Stress disrupts the digestive system, worsens the symptoms of menopause and interferes with fertility, and stress is also linked to impaired memory, weakened immune systems, high blood pressure, ulcers and skin problems. These health issues will definitely impact the ability to to be a mindful parent, managing the family.

In order to maintain the ability to be the parent, spouse, or friend you wish to be, there are several things you can practice to lessen the burdens of everyday stressors.

First, **breathe!** This is the most



## Patrick Schwarz:

### Universal Design & Curricular Adaptations

Tuesday, April 17, 2018 at 7:30 p.m.

Fox Run Clubhouse • 333 Plum Grove Road, Elk Grove Village.

Get details and register for FREE:

[www.ufdPatrickSchwarz.eventbrite.com](http://www.ufdPatrickSchwarz.eventbrite.com)



## Stress: (CONT.)

important skill you can use when attempting to

relieve stress. This is the easiest strategy to start, and it requires one to be mindful, being in the present moment, and taking slow deep breaths. Many of us try to teach our children to breathe and count to ten, but we do not often use the same method to calm ourselves.

Next, it is helpful to **visualize a relaxing and happy place** in your mind. Picture all the colors, try to feel the air, hear the sounds, etc. Keep an actual picture of the "happy place" and post it in a place where you can glance at it throughout the day. Also, teach yourself to let go of anger. A little anger can fuel you, motivating you to take action, but if there is too much anger, it is anger you can not let go, or it is displaced anger, it will, most likely, be detrimental to your health, and at the very least, leave you exhausted, both mentally and physically. Self-talk is a strategy to employ to

counteract the anger. Think positive statements and affirmations; negative thoughts make us feel negative. Along with the self-talk, learn to say your fear or speak your issue out loud, it can reduce the stress, and you can ask directly for what you want and need. This also means that you should consider expanding your circle of support, making certain that you surround yourself with positive people, and learn to ask friends for help.

Be certain to focus on your body - pay attention to how you are feeling. Though it may seem like you can't fit in one more thing, take that short walk at lunch. Understand how you feel when you are stressed, and try options to alleviate the stress through exercise.

Be certain to **get enough sleep**; it is okay to give yourself permission to take a nap! Learn to eat healthy, since a nutritional diet will lead to clear thinking. Make time for yourself--take up yoga, do a hobby you enjoy, talk to a friend.

## Maine West: B-ball, Cinderella, and more!

Maine West has selected UPS for DownS as the charity recipient for their student fundraising activities for this school year!

There are many opportunities and fun events, which so far have included a basketball game, where UPS for DownS board member Allie Reninger, along with Gina and Ali Musielski, shared information about the organization during half time. Also, UPS for DownS was the beneficiary from a performance of their musical Cinderella, as well as the funds generated from a Family Fun Fair.

Coming up on Saturday, April 14th: A Daddy/Daughter Dance featuring Disney Princesses, hair-dos, manicures, DJ, and dancing! For dads and daughters (ages 3-11). See the inserted flyer for details and to pre-register for \$25 (or \$30 at the door).

4 - March/April 2018



# JUNIOR TEEN SOCIAL CLUB

**AGES 13-16**  
and currently in  
**JUNIOR HIGH** or  
**MIDDLE SCHOOL**



## SOCCKER CLINIC FOR ALL JUNIOR HIGH MIDDLE SCHOOL AGE KIDS

WHEN: Saturday, April 14, 2018

WHERE: Schaumburg Sports Center, 1141 Irving Park Road

TIME: 1 p.m. - 3 p.m.

RSVP: [www.JRteensoccer.eventbrite.com](http://www.JRteensoccer.eventbrite.com)

Soccer clinic with two trainers where we will work on soccer skills, followed by a scrimmage game and snacks in the party room.

# ADULT SOCIAL CLUB

**AGES 21 & UP**



For adults, ages 21 and over. Just don't bring mom or dad. Watch for details about upcoming events. To be added to our list for event notifications or to share ideas for future activities, send your name and other information to [adultsocialclub@upsfordowns.org](mailto:adultsocialclub@upsfordowns.org)

## DOUBLE RAINBOW FOR WIZARD of OZ in DOUBLE CASTING



# OZ FOR ALL.

UPS for Downs Theatre Company partnered with EDGE

Constellation Project to go over the rainbow with six incredible performances of *The Wizard of Oz*. The cast and crew of seventy performed this classic musical in two locations - Al Larson Prairie Center for the Arts and West Leyden High School.



UPS for Downs is grateful to the volunteers, cast, and crew for pouring their hearts, brains, and courage into making this the best *Wizard of Oz* production in all of Emerald City and beyond. We thank the audience for your amazing love and support. The first weekend's performances were completely sold out, with well over 2,000 seats purchased online!



And finally, we thank our EDGE founder and director Orion Couling. Each and every year we say, how can we top that show? And he and EDGE do, always adding new elements to up the ante. Together, we push the boundaries of theatre, community, and social change. They share our vision for community that includes people of all abilities; they demand our very best and inspire us all to be better.



Until the next show...



*Our deepest gratitude goes to Sam Duray and Jennifer Frankfurter at [photographywithheart.com](http://photographywithheart.com) for photos of both casts.*



Go to the following links to view hundreds more images of both casts:  
Thursday/Saturday: <http://tinyurl.com/UFDoz1> - password: Saturday  
Friday/Sunday: <http://tinyurl.com/UFDoz2> - password: Sunday  
Final Dress Rehearsal/Cast photo: <https://tinyurl.com/ufdoz3>



# THEATRE CLASSES

**ALL CLASSES TAKE PLACE ON  
Tuesday evenings beginning April 3**

**TAP & SOFT SHOE, A STAR IS BORN,  
PERFORM IN A CLASSIC PLAY!**

Class registration and details available at:  
[www.ufdtheatre.eventbrite.com](http://www.ufdtheatre.eventbrite.com)

**CLASSES to be held at  
Conant High School,  
700 E. Cougar Trail, Hoffman Estates**

March/April 2018 - 7

# FAMILY FRIDAY

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

Friday, March 16 and  
Friday, April 20 at 6:30 p.m.

## KIDTOWN USA

1071 S. Roselle Rd. Schaumburg, IL

RSVP at

[www.familyfriday.eventbrite.com](http://www.familyfriday.eventbrite.com)



UPS for DownS to host  
ONE DAY FAMILY RETREAT:  
CAMP DUNCAN DAY OUT

SATURDAY, JUNE 2

Shooting arrows!

Climbing walls!

Boating!

And so much more!

Camp Duncan is a GREAT way to connect with families in a camp-like atmosphere! Spend the day with us at the YMCA Camp Duncan in Volo, Illinois. We will eat lunch and dinner at the camp and expect to end our outing with a campfire. The day will be filled with a variety of activities for children ages 5-12. Pack your sunscreen and come on out for a day filled with fun for the whole family!

Please e-mail Neil at [ngunsteen@upsfordowns.org](mailto:ngunsteen@upsfordowns.org) if you are interested in attending this FREE EVENT or have questions. Space is limited!



# PARENT NIGHT OUT

Come out and enjoy a night of informal parent support and networking with dinner at Tokyo Pub, followed by a comedy show at Laugh Out Loud in Schaumburg.

**Saturday, March 24 • Just \$20 per person.**

Actual cost is higher and subsidized by UPS for DownS.

Get more details and RSVP online ASAP. Space is limited:  
[www.PNOmarch2018.eventbrite.com](http://www.PNOmarch2018.eventbrite.com).



Mmm... Cheese... Chocolate... Fondue.  
The Melting Pot in Naperville

**Saturday, April 21 • Just \$20 per person.**

Actual cost is higher and subsidized by UPS for DownS.

Get more details now and RSVP online beginning March 25.  
Space is limited: [www.PNOmeltingpot.eventbrite.com](http://www.PNOmeltingpot.eventbrite.com).



## SAY

# Thank you!

Does your child with Down syndrome have a teacher or staff member who has gone above and beyond the call of duty? We offer you the opportunity to send a personalized UPS for DownS Certificate

of Appreciation to recognize someone you feel has exceeded expectations in helping your child or family.

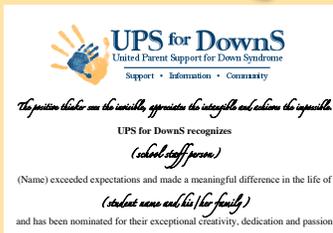
There are no requirements for requesting a certificate, other than to be nominated by an UPS for DownS family. The certificate is placed in a blue certificate holder and typically mailed directly to the principal or

supervisor. You may have the certificate(s) sent directly to you to present personally, but be sure to notify their supervisor of this recognition.

To obtain a certificate, submit:

1. The name of the teacher/s or staff member/s you wish to recognize
2. The name of the student
3. The name of the individual or family entering the nomination
4. The name and address of the principal and school (or your address if presenting yourself.)

Send your requests to [certificates@upsfordowns.org](mailto:certificates@upsfordowns.org). **Please, no more than three per family.**



# Sensory Processing & Down Syndrome

On February 20, Maureen Connors Lenke, OTR, from Developmental and Behavioral Pediatrics at Alexian Women and Children's Hospital presented "Sensory Processing in Children with Down Syndrome". Sensory processing, also known as sensory integration, is taking in information and processing and integrating information to plan and organize. The need for assistance from an occupational therapist to help with sensory processing issues arises when there is significant interference with life functions or daily living. Incessant finger chewing. Alarming head banging. Repetitive kicking. These all sound like a typical toddler temper tantrum, but sometimes, the child can actually be battling sensory issues.

Sensory Processing Disorder (SPD) can be described as a **neurological "traffic jam"**. SPD prevents certain parts of the brain from receiving the information needed to interpret sensory information correctly. Often, this means a child's behavior is compensating for an emotional, neurological need for something more than what they're getting, via any of the five senses (i.e., sight, sound, touch, smell taste). While diagnosing a sensory processing of sensory integration disorder can be complex, there are several questions that should be considered:

- Does the child's action **disrupt** your life? For example, do you avoid certain places because of noises, crowds or smells?
- Does the action occur with

everyone? For example, if a child's actions only occur with parents and not at school or day care or with grandparents, the action is likely behavioral.

- Does the child stop the action when given a reward? If a child is having a meltdown because of a sensory issue, then a sticker or a piece of candy will not fix the situation.
- If it is a sensory issue, the child will need some **specific interventions** to help regulate his or her sensory system.

Children exhibit reactions to a variety of issues which can include **taste or texture, food aversions or sensitivities, sound, with**



[www.facebook.com/upsfordowns/](http://www.facebook.com/upsfordowns/)

[www.facebook.com/charityathlete/](http://www.facebook.com/charityathlete/)

[www.facebook.com/groups/ufdexchange/](http://www.facebook.com/groups/ufdexchange/)



[@ups4downs](https://twitter.com/ups4downs)

[@charityathlete](https://twitter.com/charityathlete)



## Sensory processing: (CONT.)

**noise sensitivities, and touch, tactile defensiveness or sensitivity to clothing.** Children may also have vestibular and proprioceptive seeking behaviors, which occur when a child seeks lots of movement compared to peers or avoids movement, as well, resisting swinging on swings or playing on a playground.

If you suspect a child has a sensory issue, it is advised that you discuss your thoughts with your pediatrician and see an occupational therapy (OT) referral for an evaluation.

What should you avoid? Lenke warns that you should not rely on the therapy sessions alone to improve a child's sensory processing behaviors. It is most effective when a sensory diet is

### **carried over at home**

consistently. A therapist will provide a sensory diet based on a child's individual needs, and parents need to take an active role.

A sensory diet is a group of activities that are specifically scheduled into a child's day to assist with attention, arousal and adaptive responses. The activities are chosen for that child's needs based on sensory integration theory. The use of **specific types of input**; proprioceptive, tactile, visual auditory, vestibular, gustatory, and oral motor are introduced during various times of the day and assist the brain in regulating attention and an appropriate level of arousal. These different types of input cause a release of neuro-chemicals that can last up to two hours, depending on the type of input and intensity. A sensory diet is designed to keep a flow of these neuro-chemicals steady in the brain throughout the day for improved learning.

UPS for DownS formally recognizes the people or organizations that enrich the lives of people with Down syndrome through its "Commitment to Excellence" Award. The CTE is for recognition of those who have helped people with Down syndrome, their families and/or this organization.

**NOMINATE SOMEONE TODAY**

Nominate your educators, medical professionals, organizations, coaches, volunteer or others. Nominations are due by April 15th and must be in writing. **All information must be provided at time of nomination to be considered.**

**Nominations may be made online at [CTEnomination.eventbrite.com](http://CTEnomination.eventbrite.com)**

Questions?  
Contact Pat at PShimanek@hotmail.com



# 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

## UPS for DownS Sibling Scholarship

- One \$2500 scholarship to an individual who is pursuing a post secondary degree and is a sibling of a person with Down syndrome

## Katie MacDonald Memorial Scholarships

- Two \$2500 scholarships to individuals with Down syndrome who are pursuing educational or job training opportunities
- Two \$2500 scholarships to individuals pursuing any post-secondary degree
- Must have a personal or family connection to UPS for DownS



**APPLICATIONS MUST BE SUBMITTED BY APRIL 1, 2018**

DOWNLOAD APPLICATION AT  
[www.upsfordowns.org](http://www.upsfordowns.org)

### IMPORTANT DATES:

Deadline to apply: April 1, 2018  
Winners announced before May 1.

ANY QUESTIONS, CONTACT:  
[scholarship@upsfordowns.org](mailto:scholarship@upsfordowns.org)

## UPS for DownS

1070 S. Roselle Road  
Schaumburg, IL 60193  
847.891.2100