



# UPS for Downs

United Parent Support for Down Syndrome  
Support • Information • Community

## January/February 2019

### In this Issue

Note from the Board.....1  
 Future Care Planning .....1  
 At a Glance .....2  
 Not your average IEP .....3-4  
 Assistive Technology .....3  
 Family Friday .....5  
 Winter Swim Party .....5  
 Meagher thanks .....5  
 Sibshop .....6  
 Adult Social Club January ..6  
 Jr. Teen Social Club .....7  
 Sr. Teen Social Club .....7  
 Adult Social Club February .7  
 Holiday Party .....8-9  
 Imagine What If .....10  
 Scholarships .....11  
**BOX OFFICE IS OPEN** .....12

### Note from the Board.

Happy New Year to all. I've been celebrating with the UPS for Downs families for 23 years now. I can hardly believe that many years have passed since our first meeting so long ago when Lindsey was just a few months old. The years may have flown by, but the consistency of UPS for Downs to provide quality programming, up to date information, fun family events, and endless inspiration has continued throughout.



UPS for Downs has always been about families supporting other families. And the support comes in many ways. It may be through the monthly informational meetings,



**MARY POPPINS**

**Details on back page**

### Future Care Planning: 10 Step Process

Tuesday, January 15 at 7:30 p.m.

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

Kristen Izatt will guide participants through the confusing maze of financial and legal decisions to create plans that ensure the well-being of their families and the accomplishment of important family goals. Her considerable legal expertise includes estate planning from a parent's perspective, wealth preservation, and Medicaid eligibility planning.

Get details and register for FREE:

[futurecareplanning.eventbrite.com](http://futurecareplanning.eventbrite.com)

## At a glance...

Tuesday, January 15  
Future Planning Meeting

Friday, January 18  
Family Friday

Sunday, January 20  
Junior Teen Club Trampoline Event

Thursday, January 24  
Adult Social Club Wine/Paint party

Friday, January 25  
Senior Teen Club @ Maggiano's

Thursday - Sunday  
February 7 - 10  
Mary Poppins Musical

Friday, February 15  
Family Friday

Saturday, February 16  
Adult Social Club  
Beer & Board Games

Tuesday, February 19  
Assistive Technology Meeting

Friday, February 22  
Senior Teen Club Paint & Mingle

Saturday, February 23  
Sibshop & Winter Swim Party



1070 S. Roselle Road  
Schaumburg, IL 60193  
[www.upsfordowns.org](http://www.upsfordowns.org)  
847-895-2100



Family Friday, the swim parties, Parent Night Out, Dinner Dance, e-group, or a conversation with another parent at play rehearsal. You can always count on another parent to share their knowledge and experiences to help get you through your next round of concerns. And if it is not another parent, then you will consistently be inspired by the lives of our loved ones with Down syndrome who are working in their communities, giving speeches, going to college, writing blogs, starting businesses, taking dual language classes, playing musical instruments, voting, advocating with legislators, golfing, dancing or any activity you can think of! UPS for DownS families inspire one another to live real lives in their communities.

As we look ahead to 2019, UPS for DownS will continue its exceptional programming. Come join us on January 15 to hear how to plan for your family's future that will focus on securing a future with financial and legal decisions to help you achieve your family goals. February is full of family fun opportunities with four performances of Mary Poppins on February 7-10th, as well as our winter family swim party on February 23. And don't miss the parent education meeting about Assistive Technology on February 19.

All of the UPS for DownS programs and activities are organized by volunteers who have a vision to improve the lives of those with Down syndrome. If you have an idea, vision, or opportunity to share with UPS for DownS please contact the board of directors at [TheBoard@upsfordowns.org](mailto:TheBoard@upsfordowns.org). We welcome your input and are always looking for reliable volunteers. Ironically, our biggest need is a volunteer to manage our volunteer needs! In the words of Margaret Mead, "Never doubt that a small group of thoughtful citizens can change the world; indeed it is the only thing that ever has."

*Sandy Payerunas*

# NOT YOUR AVERAGE IEP

## A New Service for Special Education Meetings

The annual special education meeting for your child can feel daunting. As parents, we want to make sure we are able to ensure the best for our kids. Many times, however, we are unsure of how the meeting will go. What if there was a way to make the whole process feel more comfortable? The parents who braved the cold weather the Tuesday before Thanksgiving found out how to do just that. They were treated to a fantastic presentation on how the Facilitated IEP, a new state program, can help make parents feel more confident with the IEP meeting.

Michael McElherne and Sherry Colegrove from the Illinois State Board of

Education (ISBE) shared how the Facilitated IEP process can promote collaboration and bring attention to student needs. ISBE State Facilitators are specifically trained in the IEP process and how to help parents and teams prepare for a successful meeting. The free service allows for a trained professional to lead the team to consensus for each component of the IEP.

A facilitated IEP is available upon request by a parent or district. The facilitator is a well-prepared and respectful neutral third-party who utilizes problem solving strategies for a smoother meeting. They are an expert in special education and are specifically trained to help



## **Assistive Tech for Communication, Academics & Daily Living**

**Tuesday, February 19, 2019 at 7:30 p.m.**  
**Fox Run Clubhouse • 333 Plum Grove Road, Elk Grove Village**

Does your child struggle with communication, academics, or daily living skills? If so, you won't want to miss the presentation all about assistive technology! Jocelyn Kotrba, Assistive Technologist at Batavia School District, will share information about assistive technology and IDEA and a framework for selecting the right assistive technology tools for your child. She will also share information about tools that can support students with communication, academics and independently completing daily living tasks.

**Get details and register for FREE:**  
**[www.ufd\\_AT.eventbrite.com](http://www.ufd_AT.eventbrite.com)**



## IEP: (CONT.)

teams communicate with each other.

Prior to the meeting, the facilitator will contact the parent and district representative individually to gather and share information. Typically, information will be requested one week prior to the meeting. With this information, the facilitator can develop and share a meeting agenda, preferred outcomes, and group norms. The facilitator will also assemble materials for the team, including graphics, charts, and other visual tools.

time, and confirming agreements made. Facilitators emphasize “no surprises.” Changes or deviation from the agenda should be discussed at another scheduled meeting. Finally, the team will review their recorded decisions at the end of the meeting and assure that agreements have been made on all items.

Overall, parents and districts have been satisfied with the IEP facilitation process. With this type of meeting, parents and team members are better prepared and have an equal voice. In addition,



On the day of the meeting, the facilitator will arrive early to set up materials. They will begin the meeting with an overview, including outlining the agenda, explaining the visual tools available for the meeting, and describing their role. Throughout the process, they will actively listen and keep the conversation on track by recording decisions, being mindful of

meetings tend to have reduced contention, allowing for more student-focused and positive outcomes. To request or learn more:

Email: [scolegro@isbe.net](mailto:scolegro@isbe.net)  
Telephone: (866) 262-6663  
Website: <https://www.isbe.net/Pages/IEP-Facilitation-System.aspx>

# Join us INSIDE for a WINTER SWIM PARTY! Fiesta de Natacion

Splish! Splash! It's almost time for our annual winter swim bash! Your family and your kid's buddies are invited to jump in and enjoy a tropical paradise! It is the perfect time to enjoy swimming and waterslides to beat the winter cold.



Register: [www.UFDwinterswim.eventbrite.com](http://www.UFDwinterswim.eventbrite.com)

**Saturday, February 23 • Sabado, Febrero 23 • 6 p.m. - 9 p.m.**  
**The Water Works, 505 N. Springinsguth, Schaumburg**

The entire indoor waterpark is closed to the public for our private event! Concessions will be available for purchase at swim party. For questions, please contact Neil at [NGunsteen@upsfordowns.org](mailto:NGunsteen@upsfordowns.org)



For the past several years, UPS for Downs' dad Bob Meagher has completed an annual walk around Lake Geneva as a fundraiser in honor of his son Max!



This year, his buddy Brian joined in the endeavor. Special thanks and gratitude to Bob and the Meagher family's generous friends and supporters!

## FAMILY FRIDAY

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

Friday, January 18 and  
Friday, February 15 at 6:30 p.m.

**NEW LOCATION!**  
Discovery Room @ Schaumburg  
Community Rec Center  
505 N. Springinsguth

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



**Saturday, February 23, 2019**

**2:30 p.m. - 5:45 p.m.**

**FREE**

Registration required:

**[www.WinterSibshop.eventbrite.com](http://www.WinterSibshop.eventbrite.com)**

**Schaumburg Community Recreation Center (north end of building)  
505 N. Springinsguth, Schaumburg, Illinois**

Calling all siblings ages 7-14, this one is just for you! During a SibShop, siblings come together to meet one another, share the challenges and celebrations of having a sibling with Down syndrome, and continue to build their support network! A dinner of sandwiches, fruit, and veggies will be served prior to the end of the SibShop so siblings can transition with their families to the Winter Swim Party.

Adults with siblings who have Down syndrome, Adam Reninger and Sam Shimanek will facilitate an exciting afternoon of fun activities centered around building relationships with other siblings and sharing about experiences about being siblings in a supportive environment.

**QUESTIONS? Contact Sam at [SShimanek@upsfordowns.org](mailto:SShimanek@upsfordowns.org)**

**ADULT  
SOCIAL  
CLUB**

**AGES 21 & UP**



Join Adult Social Club for Paint Night - painting and meeting new people included. Cash bar available at your cost. Bring your own snacks or to share! All adults with and without Down syndrome welcome (Mom & Dad - stay home).

**WHO:** Anyone over 21. No parents, please.

**WHEN:** Thursday, January 24, 2019 from 7 - 9 p.m.

**WHERE:** Pinot's Palette, 100 W. Higgins; Suite H80, S. Barrington

**COST:** \$15 per person (UFD pays the rest)

**RSVP:** [ASCpaintnight.eventbrite.com](http://ASCpaintnight.eventbrite.com) - SPACE IS LIMITED.

**Questions:** Email [adultsocialclub@upsfordowns.org](mailto:adultsocialclub@upsfordowns.org)

# JUNIOR TEEN SOCIAL CLUB

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

WHEN: Sunday, January 20, 2019  
TIME: 3 p.m. - 5 p.m.  
WHERE: Urban Air Trampoline Park  
Springbrook Shopping Center  
140 E. Lake Street, Bloomingdale  
COST: \$5 per person (UFD pays the rest)  
RSVP: [www.JrTeenTrampoline.eventbrite.com](http://www.JrTeenTrampoline.eventbrite.com)

**URBAN AIR**  
Trampoline & Adventure Park

Questions? Contact Heather at [HVargas@upsfordowns.org](mailto:HVargas@upsfordowns.org)

# SENIOR TEEN SOCIAL CLUB

**AGES 14-21**  
and currently in  
**HIGH SCHOOL**  
or **TRANSITION**

**WHO:** High School & Transition students between the ages of 14-21, and any siblings and friends in that age group

**WHAT:** Family style Italian dinner, game, dancing and visiting with friends.

**WHEN:** Friday, January 25th, from 6:00 - 8:30 p.m.

**COST:** \$10 (UPS for DownS pays the balance)

**MAGGIANO'S**  
LITTLE ITALY

**WHERE:** Maggiano's, 1901 E. Woodfield Rd., Schaumburg

**REGISTER BY 1/18/19 AT:** [seniorteensmaggianos.eventbrite.com](http://seniorteensmaggianos.eventbrite.com)

**WHAT:** Paint and Mingle Event

**WHEN:** Friday, February 22, 6:45 - 9 p.m.

**COST:** \$15 (UPS for DownS pays the balance)

**PINOT'S  
PALETTE.**

**WHERE:** Pinot's Palette, 100 W. Higgins, Barrington

**REGISTER HERE:** [teenscenepinotpalette.eventbrite.com](http://teenscenepinotpalette.eventbrite.com)

Any questions can be directed to [seniorteens@upsfordowns.org](mailto:seniorteens@upsfordowns.org)

# ADULT SOCIAL CLUB

**AGES 21 & UP**

Join Adult Social Club for board games and beer. All adults with and without Down syndrome welcome.

**WHO:** Anyone over 21. No parents, please.

**WHEN:** Saturday, February 16, 2019 from 6 - 8 p.m.

**WHERE:** Beer on the Wall, 106 Main Street, Park Ridge

**WHAT:** Board games, beer & pizza!

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

**RSVP:** [ASCboardgames.eventbrite.com](http://ASCboardgames.eventbrite.com)

**Questions:** Email [adultsocialclub@upsfordowns.org](mailto:adultsocialclub@upsfordowns.org)



# 23rd Annual Holiday Party

Another UPS for DownS Holiday party in the books! Thanks to all who attended and made the event so wonderful. A special thanks to those who volunteered by shopping, wrapping, decorating, or assisting the day of the party. This event would not be a success without you. Save the date for next year: Sunday, December 15, 2019. We hope to see you and your family there! - Drake Krohn



All photos at link: <https://photoboothchicago.smugmug.com/Other/Ups-For-Downs-Event-12-9-18/>

8 - January/February 2019



# IMAGINE WHAT IF...

## From yo soy la lay - a blog by Maggie Lay

- What if we stopped equating *smart* with *successful*?
- What if we believed that those who are not “smart” still have something to contribute?

*Imagine a mom getting a diagnosis of Down syndrome in a world where it didn't matter if her child would be smart. What if she knew that the child would be accepted, taught, cared for, and loved regardless?*

- What if we presumed competence in all? And when someone doesn't understand, what if, instead of being frustrated, we reacted with patience and love?
- What if we stopped believing that a classroom of learners who struggle is a “dumping ground”?
- What if we stopped encouraging families touched by disability to band together in separate places and in separate communities and just embraced everyone?

*Imagine parents learning that their child has Down syndrome in a world where they knew that their schools and communities wouldn't bar them from participating in classrooms and activities. Imagine never questioning whether your child would be allowed to participate in birthday parties, field trips, assemblies, or just in plain old school.*

- What if we stopped believing that the brightest are the best and instead believed that those who are joyful, humble, caring, and kind are what we need most?
- What if we stopped seeing advocacy as a way of “helping the less fortunate” and instead just saw it as being a human being?
- What if we stopped seeing the disabled as less-fortunate altogether?
- What if we always, *always* chose kind?
- What if we could see beauty in the differences that make each of us unique?
- What if we respected people's feelings and beliefs and didn't walk through life with the attitude that a different perspective makes someone a bad person or less worthy of kindness and love?
- What if we could stop seeing another perspective as an attack on our own thoughts and feelings?
- What if we just chose love? Always.

YOU can make the difference. YOU can *be the Hands and Feet*. YOU can advocate in small ways, big ways, in thoughts, in actions, with money, with words, or with nothing but kindness.

Imagine if this is how we lived.

What if?

Maggie lives in suburban Chicago with her husband John and their three daughters. The busy family experiences a busy, chaotic family life with humor and ... well, lots of humor.

# UPS for DownS proudly announces 2019 SCHOLARSHIPS FOR

 **\$12,500**

- youth with Down syndrome
- siblings
- those pursuing any degree
- must have personal or family connection to UPS for DownS

UPS for DownS will award up to  
5 non-renewable Scholarships of

**\$2500**

## **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 a post-secondary degree
- Must have a personal or family connection to UPS for DownS

## **IMPORTANT DATES:**

Deadline to apply: April 1, 2019  
Winners announced May 1, 2019

## **ANY QUESTIONS, CONTACT:**

[scholarship@upsfordowns.org](mailto:scholarship@upsfordowns.org)

## **UPS for DownS**

1070 S. Roselle Road  
Schaumburg, IL 60193  
847.891.2100



## **DOWNLOAD APPLICATION AT:**

**[www.upsfordowns.org/scholarships](http://www.upsfordowns.org/scholarships)**

**APPLICATIONS MUST BE SUBMITTED BY APRIL 1, 2019**

**Scholarships must be used within one year of date awarded.**



**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 THEATRE COMPANY and  
E.D.G.E. Constellation Project PRESENT

Prairie Center for the Arts  
Schaumburg, Illinois

Thursday, February 7 @ 7 p.m.  
Friday, February 8 @ 7 p.m.  
Saturday, February 9 @ 6 p.m.  
Sunday, February 10 @ 2 p.m.

# MARY POPPINS JR.

**GENERAL ADMISSION**

**Presale tickets: \$15**

**At the door: \$20  
IF NOT SOLD OUT**

Shows will sell out. Get your tickets ASAP!

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

NOTE: Several roles are double cast. Pay close attention when purchasing tickets if you are coming to see a specific actor in a lead role.

Performance features actors with and without Down syndrome, friends and peers.