



UPSforDownS

United Parent Support for Down Syndrome
Support • Information • Community

April 2017

In this Issue

Note from the Board1
 At a Glance2
 Educational Rights3-4
 Parent Night Out5
 May Meeting.....5
 Commitment to Excellence5
 kiDs Club6
 Adult Social Club6
 Junior Teen Social Club.....7
 Senior Teen Social Club.....7
 Entrepreneur Panel.....8
 Social Media.8
 Advocacy Day8
 Parent Coffee9
 Family Friday9
 Family Retreat9
 Miles Count10
 Amazon Smile10
 UIC Study10
 Say Thank-you11
 Center Stage Donates.....11
 Meet Emma.....back page



Geoffrey Mikol opened his new, larger River Bend Gallery this spring in Galena. Geoffrey will be part of our entrepreneur panel on Tuesday, May 2. See p. 8.

Note from the Board.

On April 9, 1999, my world was changed forever. That is the day my first child, my son Brett, was born. To say I experienced extreme emotions on each end of the scale, would be an understatement. For the first few hours after Brett was born, I had no idea he had Down syndrome and I was beyond elated. Prenatal blood testing did not show any evidence of any abnormality. Why would it? I could envision all of his future sporting success and had big plans for him. I even came up with scenarios of his name being announced on the loud speaker in the stadium.

Later that day came the crushing blow that he had Down syndrome. In my ignorance, this came as a death sentence. From the highest of highs to the depths of despair in the blink of an eye. I had a pit in my stomach and lump in my throat. How could this happen to me? How could this happen to my son? My feeling of dread and hopelessness began to change the very next morning. We were fortunate that a friend's coworker had a 3-year old son with Down syndrome. She paid my wife and I a visit, and I will never forget her kind words as she explained that our son's future was far from inconsequential: he would walk and talk, play, run, laugh, love and have a full life.



College Options

Tuesday, April 18 at 7:30 p.m.

Fox Run Golf Links Clubhouse

333 Plum Grove Road, Elk Grove Village

Many local colleges and universities are working to make college an option for all students, including students with Down syndrome. Come learn from program representatives about the growing possibilities for postsecondary education in our area!

Get details and register for FREE:

www.ufdCOLLEGE.eventbrite.com

At a glance...

Tuesday, April 4, 2017
UPS for DownS Town Hall Meeting
Theatre Classes begin

Tuesday, April 11, 2017
Parent Coffee & Playgroup

Tuesday, April 18, 2017
College Options & Down syndrome

Saturday, April 15, 2017
Commitment to Excellence
nomination deadline

Friday, April 21, 2017
Family Friday

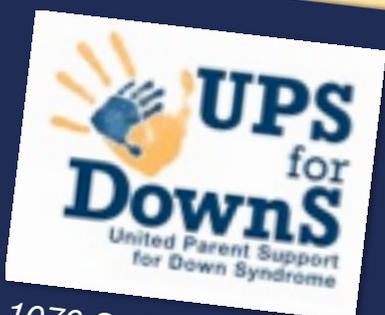
Saturday, April 22, 2017
kiDs Club: Bubble Soccer
Senior Teens: Comedy Club
Adult Social Club: Pizza Tour

Saturday, April 29, 2017
Junior Teen Scene: Yoga

Tuesday, May 2, 2017
Adult Matters: Entrepreneur Panel

Saturday, May 6, 2017
Parent Night Out

Tuesday, May 16, 2017
Sibling Panel



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



That same person also introduced us to UPS for DownS. The May grandparents' meeting was our very first outing, and my in-laws attended with us. Everyone was warm and welcoming and they were not "those poor people"; they were normal, everyday folks: just like me.



From the very first meeting, my wife Sandy and I felt connected to UPS for DownS, bonding and learning from other families. We enjoyed family events, but also quickly recognized that we were not alone. We attended monthly meetings and many of the workshops, reluctantly giving up a football or basketball Saturday. We learned about early intervention, IEP's, educational rights, special needs trusts, therapies, and much more. We were not always ready to hear or to implement what we heard, but by attending, it gave us direction and the tools to use when and if we needed them. My life has been greatly impacted by meeting and listening to people like Alice Belgrade, Paula Kluth, Patrick Schwarz and Al Condeluci.

This information has been invaluable on our journey. Brett is finishing up his junior year at Buffalo Grove High School. He on Varsity swim team, class board, plays basketball, baseball, and does competitive dance. He is looking forward to Prom. Our newest challenge, he was just diagnosed with astigmatism and will need glasses for the first time. This came as a shock to me and I'm processing it as I write this. The life lessons never end. We are now looking at what's next for Brett; post- secondary schooling, work, living situation, and adult relationships.

I have valued the role models that have blazed these trails in UPS for DownS and who have willingly and honestly shared their journey, providing support and encouragement for others. Having these mentors helps with the life challenges that raising a child with Down syndrome brings. The support and resources allowed us to make good decisions and hard choices that have been beneficial to our family. I am grateful for the opportunity to finally give back. And, I guess, become a mentor in my own right.

I look forward to meeting and speaking with you at one of our upcoming events.

Dave Wilkinson

EDUCATION & DOWN SYNDROME

On March 21, Charles Fox, special needs father and special education lawyer, gave a presentation entitled "Essentials for IEP Advocacy". An **Individual Education Plan (IEP) is the most important document that your child will have in his or her school career,** and it may be used for documentation to gain services beyond the age of 22. This is why parents of special needs students need to fully understand what an IEP is, how it is developed, what happens after it is implemented, and how this IEP will be the "roadmap" for the individual's academic, social and emotional development. An IEP is a document developed by the IEP team, which includes school personnel and parents, that outlines the individualized accommodations, modifications, special education and related services to be provided to a student in order to meet his or her specific and unique academic and functional skills.

When children with Down syndrome turn 3 years old, the law entitles them to start school in a designated program for youth with special needs. Parents and a transition team, moving from Early Intervention to Early Childhood Education, will work to place the child in the proper location for services, based on the child's academic and physical needs. This will be the first or initial IEP. Before that initial IEP, a Domain Meeting will be held, and at that time, the areas to be evaluated will be

set, which will include the following areas (domains) : hearing, vision, social-emotional status, academic, general intelligence, communication, and motor skills. The child will be evaluated for whatever concerns that are believed to be impacting the child. The evaluation will clarify the nature of possible processing deficits. The team will meet to discuss eligibility for special education and related services. It is important to note that other school professionals can also initiate an evaluation if they see your child is having difficulties in any academic or behavioral areas. It is your right as a parent that an evaluation cannot take place until you sign for consent.

The evaluations drive the determination of need, which in turn drive the IEP. It is highly suggested that you review the test versions that will be administered to your child. The most current versions of any test should be used, and it is also important to remember that many evaluations are language heavy and are timed, so students who process slowly or have a language deficit will test poorly. It would be helpful to seek other avenues of evaluation, such as "a separate nonverbal probe" and ask that the results be expressed in standardized (timed format) AND non-standardized format, allowing for extra time to be given to the student to maximize the chance of showing what the student knows. Again, the point of the evaluation is to provide the team with an accurate picture of the present levels 



of performance of the student, so accurate goals can be created for the IEP. If this is your initial IEP meeting, you will develop an IEP with the IEP team, and you will sign a consent for special education placement. If this is your annual IEP meeting, you will discuss with the IEP team how your child is progressing overall, the progress towards the goals and objectives, present accommodations and/or modifications and which placement meets their needs.

After the IEP is developed and you consent to placement, your child will begin to receive the services listed on the IEP. You will also receive a copy of the IEP. The IEP team must meet, at least annually, to review the progress of your child, their current achievements and level of performance, and whether services need to be amended. You always have the right to request a meeting prior to the annual date if you have a concern. It is important to remember that **you have a right to**

disagree with anything in your child's IEP. If you are in disagreement about your child's goals and objectives, services that they are required to receive and/or placement, first talk it out with the IEP team. If you and the school district are not able to come to a mutual agreement, you always have the option of mediation or you can file a complaint.

Mediation is a voluntary process that brings both parties (you and the school district) together with a mediator to communicate with each other and resolve your disagreements. However, it should only be used when the issue cannot be resolved in a less formal way.

You can request mediation

anytime there is a

disagreement between you and the school district about special education and/or related services. Mediation is available at no cost to the parents and all conversations are kept confidential. The end result is a written agreement that is legally enforceable. If you have already discussed your concerns at an IEP meeting and the issue has not been resolved, then mediation can be a less adversarial alternative to settle the dispute. You can work more quickly with resolving your differences through one or multiple sessions in a free and flexible way. Parents may request mediation if they feel their child needs more or different special education services, have an issue with their child's placement or do not agree with the child's eligibility.

A due process complaint or hearing request is a process that is used to resolve a formal complaint made by a parent or public agency (the school district). This process is used to resolve disagreements relating to the identification, evaluation, educational placement or provision of a free appropriate public education (FAPE) to a child who needs or is suspected of needing special education and related services. It is important to keep in mind that the due process is more time consuming, emotionally straining and costly than mediation because it is the most adversarial option. However, some parents may need to go down this road. To prepare for this process, make sure you do your research!

You may contact Charles Fox at

www.foxspeciallaw.com

PARENT NIGHT OUT



800 Hillgrove Avenue; Suite 100
Western Springs, Illinois

Date: Saturday, May 6, 2017

Time: 7:30 p.m.

Where: Davanti Enoteca

Cost: \$20 per person includes appetizers, dinner, dessert.

UFD covers the balance.

Join us for an evening of support.
Come as strangers; leave as friends.

RSVP to sneri@upsfordowns.org

Limit 24 guests



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 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

MAY MEETING: SIBLING PANEL

Tuesday, May 16th • 7:30 p.m.

Fox Run Golf Links Clubhouse, 333 Plum Grove Road; Elk Grove Village
Brothers and sisters have a longer relationship with their siblings than parents! Join us for an enlightening discussion with a panel of older teen and young adult siblings as they share their experiences. This is a don't miss meeting!

RSVP and get more information at: <http://ufdSIBLINGS.eventbrite.com>



AGES 9-12



BUBBLE SOCCER!

WHO: ALL KIDS AGES 9 - 12

WHERE: Schaumburg Sports Center
1141 Irving Park Road, Schaumburg, Illinois

DATE: Saturday, April 22, 2017

TIME: 10 a.m. - NOON

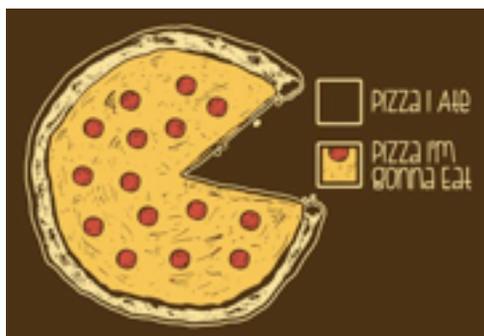
All neighbors, siblings, classmates and friends between the ages 9 - 12 with or without Down syndrome are invited and encouraged to attend.

To register, e-mail the **NAMES AND AGES of each participant** to Shawna at slochner@upsfordowns.org by Saturday, April 15, 2017. Waivers will be required of all participants.

REGISTER EARLY • LIMITED CAPACITY



AGES 21 & UP



Join us as we hit some of the best pizza places in Chicago!

WHAT: Pizza Tour of Chicago

WHERE: Meet at UPS for DownS office

WHEN: Saturday, April 22, 2017

TIME: Meet at 10 a.m. - 3:00 p.m.

COST: \$10 per person

RSVP: <http://ASCpizzatour.eventbrite.com>

All friends, siblings and colleagues age 21 and over, with or without Down syndrome are invited and encouraged to attend.

No parents, please.



AGES 13-16

intended for
**JUNIOR HIGH &
MIDDLE SCHOOL**

WHEN: Saturday, April 29, 2017

TIME: 1:00 - 3:00 p.m.

WHAT: Yoga Class

WHERE: TriBalance Yoga, 1158 S. Roselle Rd., Schaumburg

COST: FREE for all junior teens (ages 13-16)

RSVP: www.ufdteenyoga.eventbrite.com

We encourage you to bring a guest, such as another student, friend, neighbor or family member who is between the ages of 13 and 16. Not just for participants with Down syndrome. All are welcome!

Questions: Contact Heather at hvargas@upsfordowns.org or 630-667-6920



AGES 14-21

intended for
**HIGH SCHOOL
TRANSITION**

Friends who Eat Together,
Laugh together!
Join us for Dinner & a Family-
Friendly Comedy Show

WHO: For teens with Down
syndrome and their friends/
siblings who are within the ages of 14-21.

WHEN: Saturday, April 22

TIME: Meet at Meatheads at **5:30 p.m.** for dinner and
then walk to Laugh Out Loud. Pick-up is at **9 p.m.**

WHAT: Meat Heads & Laugh Out Loud Comedy Club

WHERE: Streets of Woodfield, 601 N. Martingale Road,
Schaumburg, Illinois

COST: UPS for DownS will cover the admission for comedy
club. Bring your own money for dinner.

YOU MUST RSVP by Wednesday, April 12 as we will preorder
tickets.

www.meatheadslaughoutloud.eventbrite.com

For questions, please contact the Teen Scene Crew at
SeniorTeens@upsfordowns.org





www.facebook.com/upsfordowns/
www.facebook.com/charityathlete/
www.facebook.com/groups/ufdexchange/



@ups4downs
 @charityathlete

ADULT MATTERS: EMPLOYMENT SERIES ENTREPRENEUR PANEL

Tuesday, May 2, 2017

7:00 - 9:00 p.m.

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

Come hear entrepreneurs share their experiences
 with starting up and running their own businesses.

Allison and Pat Fogarty of "Lunch Break"

Kelly and Karen Neville of "Special Sparkle"

Geoffrey and Paul Mikol of "River Bend Gallery"

Sign up and get more information:
www.ufdENTREPRENEURS.eventbrite.com



Advocacy Day
Wednesday
May 24, 2017

**& equality
 opportunity
 improved
 quality of life.**

**Illinois State Capitol
 Rotunda
 Springfield, Illinois**

**Join hundreds of self-advocates
 and allies in speaking up and
 speaking out in support of
 community living for people with
 disabilities.**

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

For more information, visit
www.goinghomeillinois.org or contact
 Krescene Beck
 at The Alliance at
krescenebeck@gmail.com or
 618-806-9431

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

PARENT COFFEE & PLAYGROUP

ALL AGES WELCOME!

NOON - 1:30 p.m.

Tuesday, April 11

Friday, May 5

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

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 21, 2017
at 6:30 at

KIDTOWN USA
1071 S. Roselle Rd. Schaumburg, IL

RSVP at

www.familyfriday.eventbrite.com

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

SATURDAY, JUNE 4

Shooting arrows!

Climbing walls!

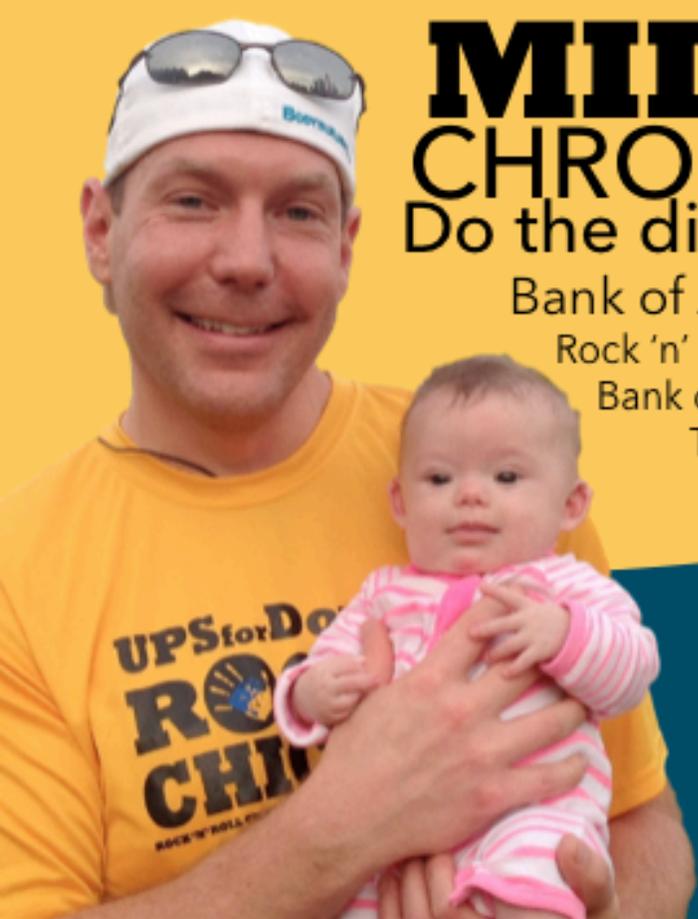
Boating!

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 if you are interested in attending this FREE EVENT or have questions. Space is limited!





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
The Super Run Chicago 5K

marathon@upsfordowns.org

upsfordowns.org

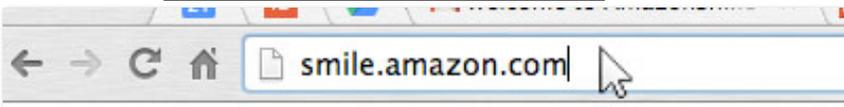
UPS FOR Downs RUNS CHICAGO

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!

10 - APRIL 2017

Down Syndrome Research Study

in need of additional participants:

- Do you or one of your family members have Down syndrome?
- Is the person with Down syndrome between the ages of 18 - 40?
- Do you want to find out more about whether exercise can improve the cognitive function of individuals with Down syndrome?

Study takes place at UIC in Chicago. For details, contact Tommy Wee in Rehabilitation Science Department:

312.996-9607
swee3@uic.edu

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? As we approach the end of the academic year, 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 to the principal of the school so that the recognition can be noted in the teacher's or staff member's file. You may have the certificate(s) sent directly to you, so that you may personally present it 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 (i.e. Jane Doe or the Doe Family)
4. The name and address of the principal and school (or your address if you will present it yourself.)

Send your requests to certificates@upsfordowns.org. **Please, no more than three per family.**



The positive thinker sees the invisible, appreciates the intangible and achieves the impossible.

UPS for DownS recognizes

(school staff person)

(Name) exceeded expectations and made a meaningful difference in the life of

(student name and his/her family)

and has been nominated for their exceptional creativity, dedication and passion.

Center Stage Dance Studio Performing Troupe performed on February 12, along with sixteen other acts at the annual production, where the organization raised \$500 and have generously donated to support the work of UPS for DownS. Their thoughtfulness and consideration are deeply appreciated!





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

EMMA SUZANNE
Nickname: Emma Sue

DATE OF BIRTH: November 2, 2014

OCCUPATION: Full-time Toddler

LAST BOOK READ:

Little Blue Truck - BEEP BEEP!

FAVORITE THING ABOUT SCHOOL:

Show & Tell

HOBBY:

Telling my baby brother "No no no!"

FAVORITE FOOD: ANY type of fruit

FAVORITE MOVIE(S):

Signing Time or Bubble Guppies

LATEST ACCOMPLISHMENT:

Saying and Signing "I love you" to my parents.

QUOTE: "I did it!"

JOKE: "Where did the sheep go on vacation? The baaaahamas!"

