



UPSforDownS

United Parent Support for Down Syndrome
Support • Information • Community

Summer 2017

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Note from the Board.

Dear UPS for DownS families,

There is a person in my life that has been a driving force through many of my experiences and opportunities; my brother Jacob. Despite any preconceived odds that may be stacked against him by a societal norm, Jacob is an involved and social member of our community. He serves at mass at our church, walks the dogs around the block, knows many of our local library's librarians, and texts my brother and me at any hour of the day.

From a young age, I learned how other people in my community did not always see Jacob in the same light as myself. This was confusing to me, how does one extra chromosome set him aside from any other person? It was understood that any member of our family can and would be able to do anything we were passionate about and worked towards. Jacob may need some support to accomplish his goals, but I feel that everyone does in their own ways; I have to get multiple opinions on what to wear or ask for



Summer Social

Dinner/Swim/Fun Activities

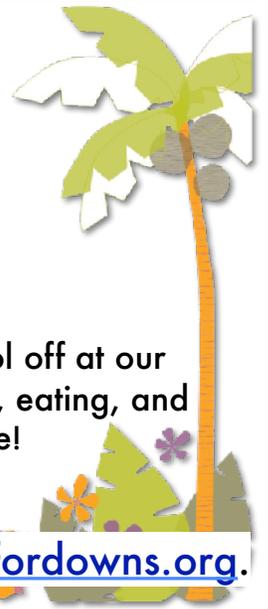
Saturday, August 26, 2017 • 6 p.m. - 9 p.m.

Schaumburg Water Works

It's summer! Your family and your kid's buddies are invited to jump in and cool off at our Summer Social. Celebrate one of the last weekends of summer with swimming, eating, and playing! If swimming is not your thing, come and bounce, dance, and socialize!

www.ufdsummerswim.eventbrite.com

Interested in volunteering or more information, contact Neil at ngunsteen@upsfordowns.org.



At a glance...

Mondays at 7 p.m.
Walking Club in Palatine

Friday, July 21, 2017
Family Friday

Saturday, July 27, 2017
Parent Night Out

Saturday, August 5, 2017
Charity Car Show

Monday, August 7, 2017
Picnic & Playdate in the Park

Friday, August 18, 2017
Family Friday

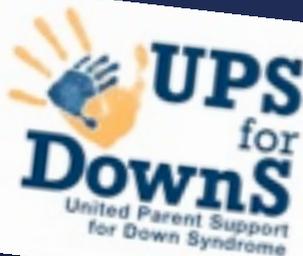
Saturday, August 19, 2017
Super Run Chicago 5K

Saturday, August 26, 2017
Wizard of Oz auditions
Sibshop
Summer Social: Swim Party/Dinner

Tuesday, August 29, 2017
Wizard of Oz auditions

Tuesday, September 5, 2017
Wizard of Oz auditions

Tuesday, September 19, 2017
IEP Boot Camp



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



feedback when I am compiling resources for a lesson plan. My family continues to share and grow with our communities as we all learn more about how to better process and live in the world around us. This has allowed me to be a stronger advocate with my brother as well as for my students in my classroom.

Through SibShops, family events, and my own educational pursuits, I have met a myriad of other siblings who understand the wonders of growing up with a sibling with exceptionalities.



These relationships have been refreshing as other sibs “get it” and understand the functioning of our families that we see as typical but an outsider may see stark distinctions from their own. It’s almost like our own language; the silent nod and eye contact across the room of “I understand, how can I help?” and the response of “Oh yea, I’ve said that to Jacob before too!” when another sib asks about getting ready for an event.

UPS for DownS has been an integral part of my family over the past years through the consistent support, community activities and integration, and educational pathways. I love being part of our inclusive theatre program with EDGE as we continue to support social and theatrical growth and discussing with different groups of siblings the triumphs of being a sibling of someone who has Down syndrome within SibShops (see p. 10 for details on our next Sibshop). I hope to continue this tradition with being a part of the multitude of opportunities of the UPS for DownS community because I cannot wait to support Jacob’s next endeavors. Thank you for being part of this fantastic community and I look forward to seeing you at any of the great upcoming summer events!

Sam Shimonek

SIBLINGS & DOWN SYNDROME

On May 16th, the monthly meeting featured our annual Sibling/Friend Panel Discussion. Whether your child with Ds is an infant or an adult, it is helpful to hear and understand perspectives of the other children in the family and individuals who consider themselves friends of your child. Our panel consisted of siblings: Frank Cassata, Anna Neri, Alana and Maya Herr, Ryan Stark, and friends: Michaela Maloney and Bridget Gawlik. Sometimes, we fear that having a sibling with Down syndrome will be a burden or is unfair to our other children, and our family experience will not be "typical". According to our panelists, this is a huge misconception.

In 2011, Dr. Brian Skotko found in a study conducted at Children's Hospital Boston, "among siblings ages 12 and older, 97 percent expressed feelings of pride about their brother or sister with Ds and 88 percent were convinced they were better people

because of their sibling with Ds. Parents in the audience asked the panel, "How do you deal with the redirection of attention and focus to your sibling with Ds?" Frank Cassata, an older brother, responded to this question, "I would rather feel valued for being a compassionate and caring person and helper than given undivided attention and exclusive use of my parents' time and resources. **My parents did a good job expressing their appreciation for the help and empathy I could contribute.**" Many of the other panelists expressed the same sentiment, whether they, too, were older siblings, or younger siblings, like the Herr sisters. Ryan Stark, a younger sibling, added, "**We don't always have it all together.**" We still can get on each others' nerves. Just because we can feel more accepting and get to try practicing more patience doesn't mean that our relationships with our siblings are less crazy. I love my brother,



Friday, October 20, 2017

The Cotillion in Palatine

\$100 per guest



A Whole New World

Invitations will be mailed in September. Put the event on your calendar today! If you have never received an invitation to this event or wish to add friends and family, e-mail us at info@upsfordowns.org.

A
Night
at the
Oasis

Want To Give Back to UPS for Downs?

What better way than helping us raise money through our annual Dinner Dance! Donate items for our silent auction and raffle. Here are some simple ideas of items you can mail to the office: Gift cards to restaurants, fast food places, car washes, oil changes, gas stations, hair cuts, manicure/pedicure or other spa treatments, scratch off lottery tickets! Or donate money and we'll pick something out! Any and all amounts are welcome! Contact Lora at dinnerdance@upsfordowns.org



but it annoys me that his emotions can be more intensive, and they are hard to deal with. Sometimes we (the family) give in to him because it is easier." Others on the panel also expressed that the "stubbornness" of the Ds sibling is one of the most difficult issues to deal with, but parents should remember that the **expectations that are set for family behavior applies equally to all children in the family.** If consequences are earned due to poor behavior, follow through with the consequence, even if it feels "easier" or more convenient to let the child with Ds "slide".

All the panelists believe that they have developed stronger families because of the Ds sibling. Alana Herr, whose brother Zane is 10 years older, explained that although Zane may be older and a boy, the family bond is very strong. "My brother has helped our family form a stronger bond and a belief that we're all in this together. **I also feel particularly fortunate to have a brother who expresses his happiness so freely.**

When Zane is happy, which is often, he will let you know; he will laugh and insist that you laugh along with him." Anna Neri added, "I never hide my sister, Julia's story. She was always included in the neighborhood. She played with all the girls I played with, and we went to the same schools. When we were in high school, Julia seemed to have more friends than I did. She always had activities to attend. I am glad that typical people made efforts to include Julia at school and in the community. " Michaela Maloney was one of the friends that Julia played with as a child, and she is still friends with Julia today. Michaela explained that she didn't actually remember a specific time when she was introduced to Julia. "Julia was just included in all our games and activities in the neighborhood. She wasn't someone who was "different"; she was just Julia." Michaela still gets together with Julia when she is home from school. Bridget Gawlik is a childhood friend of Zane Herr, and she has Zane help her

as an Assistant Volleyball Coach. Bridget had contemplated becoming a special education teacher because of her friendship with Zane. Although Bridget realized this was not her true calling, what she did realize, without a shadow of doubt, was that **she wanted to work as someone dedicated to changing society's attitude towards people with Down syndrome** or other intellectual disabilities, "I want people to make an effort to teach kids and adults about disability awareness, so we can break down the irrational and unfounded fears of the unknown associated with disabilities. Zane is one of my best friends."

When asked what the future will hold for expected sibling responsibilities regarding care or involvement in the Ds sibling's life, panelists responded with genuine and thoughtful comments. In general, they all expressed ideas of remaining involved with the sibling and not feeling burdened, as Frank Cassata remarked, "I picture having an active role in Cristina's life. I also hope to have a family and include her in my family activities. I also want to help her maintain the relationships she has worked so hard to make and maintain over the years, some with my friends and our family and some she has made on her own. I also think Cristina would make a great speaker or mentor. She is smart, and I know she would love to share her experiences. **I plan to always include Cristina in my life.**" We also asked the panel to give the best piece of advice to us, as parents, and Maya Herr provided it, "I would tell parents to find a way to keep doing things as a family regularly- despite stressful times. Having someone with Down syndrome in the family has its daily ups and downs, and it's a challenging and rewarding path. I wouldn't want to know who I might be today without my brother, Zane, in my life. I am so very proud of him and feel blessed to have him as a brother."

Camp Duncan Family Retreat

Families enjoyed a sun-filled fun day of rock-climbing, tie-dyeing, kayaking, paddle-boating, and camaraderie at the annual UPS for DownS Family Retreat.



Mondays at 7 p.m.
(weather permitting)
now through August 28
Hamilton Park Playground
1037 N. Smith Road, Palatine

All fitness levels, ages (and strollers) welcome!
Bring friends! Walk on .9 mile track.
Water and healthy snacks provided.

Get more information at link; sign up encouraged, but not required:
www.walkingclub2017.eventbrite.com

Questions? Contact WalkingClub@upsfordowns.org

We are again the CHARITY PARTNER for Super Run Chicago 5K.
Train with us! See back page for additional details.

2017 UPS for DownS Scholarship Winners

At UPS for DownS we are excited about the opportunity to give young people in our community assistance in pursuing their life goals. This year we will be awarding \$2,500 scholarships to each of the following recipients through our scholarship programs.

The 2017 Katie MacDonald Memorial Scholarship for an individual with Down syndrome is awarded to:

- Jacob Nelson, Winthrop Harbor, Illinois

The 2017 Katie MacDonald Memorial Scholarships for individuals pursuing degrees in a disability related field are awarded to:

- Akash Patel, Hoffman Estates, Illinois
- Ashley Boldt, Arlington Heights, Illinois

The 2017 UPS for DownS Scholarship for the sibling of an individual with Down syndrome is awarded to:

- Molly Doran, Wheaton, Illinois

Theatre class performs Shakespeare's Romeo & Juliet



UPS for DownS along with our partners from the Constellation Project of E.D.G.E of Orion Theatre broke new ground by performing Shakespeare's Romeo and Juliet at the Laugh

out Loud Comedy club in Schaumburg. The show was a thorough success as young people, both differently-abled and typically functioning, took one of history's most famous stories and made it their own. By the show's end, audiences didn't see actors of different abilities, they saw a community of young people telling a story together.

This was the first time that the UPS for DownS Theatre Company presented a non-musical. Diving straight into Shakespeare's language was a daunting task that the cast handled with passion, care, and dedication, working tirelessly to understand the nuances of the language and make sure that their audience would be able



CASTING CALL FOR ALL:

JUNIOR ENSEMBLE: ages 6 - 9

SENIOR ENSEMBLE: ages 10 - adult

AUDITIONS ARE:

Saturday, August 26 from 1 - 4 p.m.

Tuesday, August 29 from 6 - 9 p.m.

Tuesday, September 5 from 6 - 9 p.m.

Get details and register for your audition slot at
www.OzAuditions.eventbrite.com

Cost: \$110 per actor
(underwritten by UPS for DownS)

Rehearsals begin on Tuesday, September 12; Saturdays added October 14; at Conant H.S. in Hoffman Estates

Serious commitment required. Space is limited.





➡ to follow the tale of star-crossed lovers in a rehearsal period of just 7 weeks. These young people pursue excellence everyday in a world that often tries to tell them that they can't do things, but they did it - with excellence! Whether learning long monologues of tricky language, emotional commitment of showing love on-stage, or fighting with the real steel of swords in their hands, the cast of



Romeo and Juliet put on a truly wonderful show and thrilled audiences!

Volunteer opportunities.

We are grateful to all of those who volunteer their time so generously. Without you, this organization would not exist. If you have given thought to helping out, but weren't quite sure what was needed, please take a look at this list of critical needs and think about how you can support inclusive lives for people with DS and their families.

New Parent Welcome: 1 person to organize, maintain and send out new parent packets

Calendar Committee: 1-2 people to assist with mailings, proofreading, calendar orders

Volunteer Management: Contact and follow-up with volunteers who reach out to UPS for Downs in matching their skills and interests to organizational needs.

The passion and commitment of families built UPS for DownS. If you have time, questions, interest or ideas: contact Sandy at spazerunas@upsfordowns.org or Terri at TDevine@upsfordowns.org

PARENT NIGHT OUT



TOPGOLF

699 W. Thorndale, Wood Dale, IL

Date: Saturday, July 22, 2017

Time: 7:00 p.m.

Cost: \$25 per person includes dinner & 2 hours of golf
UFD covers the balance.

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

RSVP to singlad@aol.com

Limit 15 guests



See inserts for information about upcoming events.



Charity Car Show

Saturday, August 5, 2017
Fuddrucker's in Schaumburg
mccassata@upsfordowns.org



Famous Puzzler Rallye

Saturday, September 16, 2017
Firestone at Woodfield
www.puzzler.eventbrite.com

LOOKING AHEAD

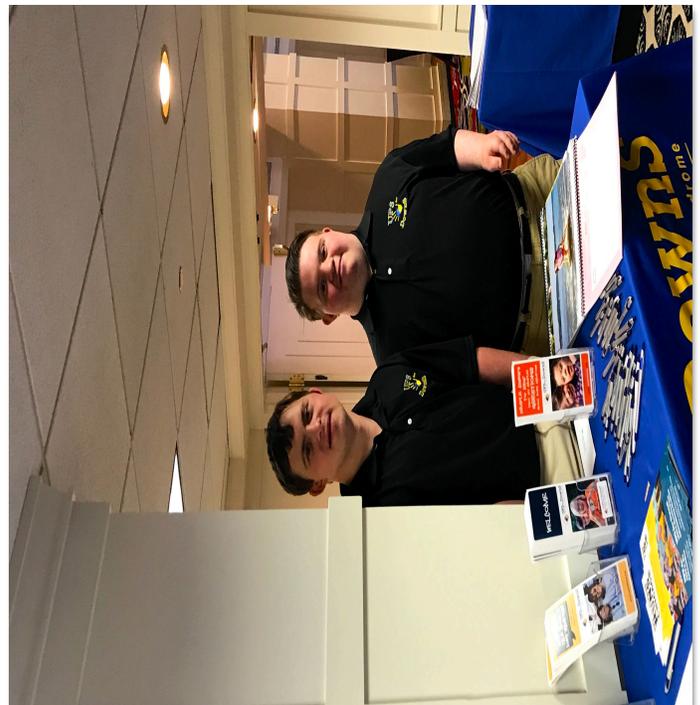
Back to School IEP Boot Camp

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

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

Learn and/or refresh your knowledge about IEP's. Catherine Whitcher, M.Ed. is a passionate advocate and experienced special educator who will get you into shape for the school year!

Get details and register for FREE:
www.ufdIEPbootcamp.eventbrite.com



Danny Orlando and Jacob Shimanek represented UPS for DownS at the Global Down Syndrome Foundation's pre-conference day at the International T21 Medical Research Conference. Both men (along with their moms) participated by donating blood and saliva for a study to research genomes in people with Down syndrome.

PARENT COFFEE & PLAYGROUP

ALL AGES WELCOME!

SUMMER PICNIC@
Grealish Park

1350 E. Joyce, Palatine

NOON - 1:30 p.m.
Monday, August 7

Bring a picnic lunch. Babysitters 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).

Friday, July 21 at 6:30 and
Friday, August 18 at 6:30 at

KIDTOWN USA

1071 S. Roselle Rd. Schaumburg, IL

RSVP at

www.familyfriday.eventbrite.com

KNIGHTS CONTINUE THEIR SUPPORT AND COMMITMENT TO UPS FOR DOWNS

UPS for DownS is grateful to the Knights of Columbus for their continued support of the mission of UPS for DownS.

Thank you to Sean O'Leary - Grand Knight, Brad Carey - Treasurer, and all the Knights of Council #1911 in Elmhurst. Allie Reninger represented UPS for DownS and accepted a recent donation.



UPS for DownS dad Dan Bak was instrumental in garnering an amazing donation when his friend Karl Albrecht decided to participate in Portfolios with Purpose, a platform for investors at all levels to engage in a friendly competition that highlights philanthropy and awareness for nonprofits. Karl came in second place in the Novice class, earning a donation of \$12,966 for his chosen charity, UPS for DownS. Karl, as well as Dan and his daughter, Sarah Bak, made the trip New York City to participate in the Awards Night Gala!

Top 5 Ways to Build Sibling Connections

1. Join your family for one of our fun family events!
2. Be a teen volunteer at family events like Family Swim, Holiday Party, or Family Friday
3. Come out for social group events for your age group even if your sibling with Down syndrome is in a different age group
4. Join our theatre program for Wizard of Oz
5. Sign up for this SibShop!



CALLING ALL SIBLINGS BETWEEN THE AGES OF 7 AND 15

WHEN: Saturday, August 26, 2017

TIME: 4:00 p.m. - 6 p.m.

WHERE: Schaumburg Community Center (north end of building)
505 N. Springinsguth, Schaumburg, Illinois

COST: FREE

www.UFDsibshopsummer2017.eventbrite.com

During a SibShop, siblings will come together to meet one another, to share in the challenges and celebrations of a having a sibling with Down syndrome, and continue to build their support network!

For questions, contact Sam at samantha.shimanek@gmail.com

Youth Volunteer of the Year winners follow family example



Sisters Marissa and Samantha Parcell are the 2017 Youth Volunteers of the Year. Despite their youth, these young women have volunteered for over four years for UPS for DownS with the Car Show, the Holiday Party, the Endurance Team and much more. They are always enthusiastic and generous volunteers. With no expectation of thanks, always ready to help with a smile.

The entire family are generous with their time and talent; Marissa and Samantha set a great example for their younger siblings, who look forward to helping out, too.

2017 Commitment to Excellence Recipients

Mary Ann Jahrling:

Mary Ann is a guidance counselor at John Hersey High School in Arlington Heights for students with disabilities. Besides being a guidance counselor, she helps with Dynamite Dancers, Super Singers, and has been the staff sponsor for all Super Buddies activities for over six years. Dynamite Dancers is a dance group that promotes inclusion & friendship between students with disabilities and typical peers. Super Singers is a choir group with students with disabilities & typical peers. They perform at the Holiday Choir Show and at the Hersey High School Holiday assembly. Super Buddies involves typical peers participating year round forming a positive rapport with students in the life skills program. It has created many friendships while providing fun activities for students to attend outside of school. She is also a lifeline for teachers. She not only cares about the students like they are her own children, but she treats the teachers the same way. Mary Ann also helps with the parent information nights. She is and always has been a huge supporter for inclusion. Mary Ann is an amazing woman who is always does her best to include and advocate for students with Down syndrome and other disabilities.

Bridget Brown:

Bridget Brown is a successful young woman who captures the attention of everyone she meets with her vitality and confidence. Bridget redefines the term "inclusion" by being the first person with Down syndrome to be included in her school district. She is a national public speaker and shares tools and strategies she used to be successfully included. She is a person centered planning coach and works with young adults with disabilities to help them find their own voice. In addition to her workshops and speaking engagements, Bridget works as part of a grant through the Illinois Council on Developmental Disabilities to help young adults with disabilities learn how to set goals, and speak with self-determination. Bridget is a graduate of the STARS advocacy program; she is also a Dental Health Educator at University Of Illinois Chicago. Bridget leads a full and productive life, keeping busy with work, church and hobbies such as reading, drawing, and writing her memoirs.

Jennifer Frankfurter:

For the past several years, Jennifer Frankfurter, who owns her own studio called Photography with Heart, has donated her time and talent in photographing our theatre productions. She is sure to attend multiple performances so that she can create memories for both casts, taking photos of the performance, as well as candid and posed shots backstage. She then edits and makes her images available to all - for free. She has also photographed our theatre classes and shares these images as well. She asks nothing in return for this generous contribution of her talent. She truly has shown a commitment to the organization and our families and allows us to capture the unique moments that form such memories and representations of our organization.





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

THE SUPER RUN HEROES vs VILLAINS

UPS FOR DOWNS IS THE LOCAL CHARITY PARTNER FOR

SUPER RUN CHICAGO!

DATE: SATURDAY, AUGUST 19

LOCATION: BUSSE WOODS, ELK GROVE VILLAGE

WHAT: 5K FOR ALL AGES!

REGISTER: [HTTP://TINYURL.COM/SUPERRUN2017](http://tinyurl.com/superrun2017)

CHOOSE "TEAM RUNNER" AND JOIN UPS FOR DOWNS TEAM!

SET UP A TEAM FUNDRAISING PAGE HERE:

[WWW.CROWDRISE.COM/THE-SUPERRUNCHICAGO](http://www.crowdise.com/the-superrunchicago)

FUNDRAISING GOAL IS JUST \$100 PER RUNNER.



USE CODE: UPSFORDOWNS
TO GET A \$5 DISCOUNT &
A \$5 DONATION TO UFD

