

DSani

DOWN SYNDROME ASSOCIATION of Northeast Indiana

January - March 2017

Issue One

Volume One

Quarterly Newsletter

HAPPY NEW YEAR! We have had a number of requests to bring back the newsletter, so here is the first! While it is currently a work in progress, we welcome your feedback. If any of you would like to work on the newsletter on a quarterly basis – we welcome your help!

Typically, you'll find a quarterly Calendar of Events to help you plan your family's activities. You'll also find a "Save The Date" section with other important dates to plan for.



There will also be sections that outline what activities each age level group is planning. A "Member Spotlight" section on activities, milestones & accomplishments of our members will also

be featured in each newsletter. This is where you come in – we LOVE to hear about things that are important to you and your family! **Any time you have a tidbit you'd like to share with our DSANI family – please feel free to send it, and a picture if you wish, to: administrator@dsani.org.** We will do our best to include it in the next newsletter!

You'll also find out about the latest advocacy, medical and research news that we have to share. Also included will be any other news or information available at the time of publication.

Please understand – you will still get emails from DSANI announcing news and activities pertinent to our families! These emails are able to provide more in-depth information than what can be included in the newsletters.

Newsletters will be posted on DSANI's website (www.dsani.org) and will be emailed out to you as well.

Speaking of DSANI's website – we are in the process of significantly updating the website and its usability to DSANI members! This will take some time, but we will keep you informed throughout the process! **We are looking for a webmaster...if you have experience in updating websites, and would be willing to help us as information needs updated, features need added, etc., please contact** the office (administrator@dsani.org or (260) 471-9964).

MEMBER SPOTLIGHT

DSANI member, **Elijah E.** was recently elected Homecoming

King at his high school!! Elijah is also a member of the Soul Brothers Dance Troupe. We are so proud of you, Elijah, and of all of your many accomplishments! We can't wait to see what the future holds for you!



Adams Central 2016
Homecoming King Elijah E.

DSANI self - advocate **Jacob R.** flew down to Orlando, Florida at the end of October and attended the ARC convention where he saw the keynote speakers, the cast of the Emmy award winning show on A&E "Born this Way".

He watched the cast during their opening general session Q&A interview, then got to sit with them for pictures and finished it off with a three hour pool party

where he ate, danced and mingled around them. Jacob met many people from all over the world while attending the convention, he also stopped in for some fun at Disney World and Universal Studios.



Jacob R. & The "Born This Way" Cast

SAVE THE DATE!

Looking ahead to the second quarter and beyond, the following are dates to add to your calendar:

- 4/25 Annual Meeting
- 5/5 DSANI Talent Show (Self-Advocate/Friendship Club)
- 5/13 DisAbilities Expo
- May DSANI Zoo Day – Date TBD
- 6/9 D.A.D.S. Golf Outing
- 7/20-23 NDSC Conference
- 7/29 DSANI TinCaps Night
- 9/8 Buddy Walk Pre-Party
- 9/9 BUDDY WALK!!**

More information on each event will be available as the time approaches.

BUDDY WALK COMMITTEE PLANNING MEETING

Would you like to be on the Buddy Walk Planning Committee? If so – please plan to attend our first meeting of the year, on **Monday, February 13**. We will meet **at 6 pm at Turnstone** (3320 N. Clinton). It takes many people to pull off a successful Buddy Walk – and we'd love to have your help and ideas!

ADVOCACY CORNER

What is advocacy? Advocacy involves actions taken by concerned citizens to demonstrate their support for an issue. In the case of Down syndrome advocacy, these issues are usually related to education, healthcare, research, employment and transition.

It's important that advocates for the Down syndrome community engage with federal, state and local government and make their voices heard. There are several ways that NDSS supports these types of advocacy efforts. Above anything else, the key to effective advocacy at any level of government is to build relationships with elected officials in order to educate and influence their viewpoints on critical issues and legislation facing the Down syndrome community.

An excerpt from ndss.org. See more at: <http://ndss.org/advocacy/advocacy-101/What-is-advocacy/>

There are a number of ways to become more involved in advocacy matters! Whether it's being involved in the Buddy Walk on Washington, where you meet with federal lawmakers; bringing Down syndrome awareness & acceptance to schools and the community; advocating for your student, etc, there are a myriad of ways to let YOUR community know how important issues that affect your family are to you!

Please join us as we move forward on this very important endeavor!

NDSC SCHOLARSHIP CONTEST RETURNS

DSANI will again be sending one family to the NDSC Conference in Sacramento, California from July 20-23!!

Just as last year, we will be offering interested families the opportunity to complete a scholarship application for their chance to win up to \$3,000 in Conference expenses. Applications will be emailed to you on March 1, and are due back by March 31. You must be a member in good standing to apply.

The NDSC Conference is a tremendous opportunity to attend many workshops on broad ranging, but very pertinent topics to the Down syndrome community. You will also have the opportunity to network with other families from all around the country and the world.

FIRST QUARTER PROGRAMMING

PLEASE NOTE – *Details about all events will be emailed to you prior to each event.*

TEXAS ROADHOUSE – 10% NIGHT

- **Monday, February 20 4-9 pm** @Texas Roadhouse on Washington Center Road

DSANI receives 10% of each check when the flyer mentioning DSANI is presented to your server. The flyer is on page 7, and will be emailed to you closer to the date, and will also be available on our Facebook page.

SPECIAL NEEDS TRUST WORKSHOP

- **Tuesday, February 21 6 – 8 pm** @ Turnstone

Local attorney Kristin Bilinski will lead the workshop. Topics discussed will include the importance of a special needs trust, information to be considered when planning a trust, and more! It's never too early to begin planning!

DSANI NIGHT WITH THE MAD ANTS

- **Friday, February 24 7 pm** Coliseum

Tickets are free to DSANI member families (immediate family only) who request tickets! The Soul Brothers and Soul Sisters will perform at half time! We'll even have an honorary team captain introduced before the beginning of the game. We will need a few self-advocates to help sell programs before the game! If you're interested, please contact the DSANI office at administrator@dsani.org.

TRANSITION IEP WORKSHOP

- **Tuesday, February 28 6 – 8 pm** @ Turnstone

David Goetz, from INSource, will lead this workshop on issues concerning IEP transition plans for those graduating from high school.

IEP WORKSHOP

- **Wednesday, March 8 6 – 8 pm** @ Turnstone

David Goetz, from INSource, will lead this information workshop, geared toward parents with pre-school and school age children. Topics to be discussed will include your rights pertaining to the IEP, how to best communicate with your student's school, special education laws in Indiana, and more.

WORLD DOWN SYNDROME DAY EVENT

- **Saturday, March 18**

Details to be announced!

TRANSITION FAIR

- **Wednesday, March 22** ACPL Downtown Branch
11 am – 1 pm and 5 pm – 7 pm

This event, sponsored by Transition Partners, is an informative "one stop shop" for families with small children all the way to those graduating from high school.

SOCIAL GROUPS ROUNDUP

Our different social groups are busy planning activities for 2017! Before going any further, we would like to give a **BIG SHOUT OUT** to our Committee Chairs!! These are the folks who work hard to bring activities to you and your families to enjoy!! We are so grateful to Sam Gray, Anna Powers, Stacey Foust, Jessica Fosnaugh, Penny Eguia, Rita Augustin, Kathy Meeks, Jason Martin, Uriel Castillo, Jennifer Cordray, Angel Castillo, Deb Clark, Jackie Geimer, Stacie Christle and Annie Miller for the hard work and effort that all of you put in to planning activities for our specific groups! **We appreciate you immensely!!**

INFANT/TODDLER PLAYGROUP – The Playgroup will meet on **Saturday, January 28 from 4-6 pm.** at the home of Kathy & Tim Whiteman. *Please bring a dish to share.* For more information and to RSVP, please contact: samgray.dsani@gmail.com. Other activities, dates and times will be shared as they become available.

BUDDY CLUB – The Buddy Club will gather on Saturday, February 25, from 2- 5 pm at Andorfer Commons (on the Indiana Tech Campus). Set up begins at 1:30 and clean up will last until 5:30 pm. More information to follow. For questions, please contact Stacey Foust at: foustjs@gmail.com.

FRIENDSHIP CLUB – Crazy Pinz, on Lima Road, will be hosting the Friendship Club on **Sunday, February 12 from 1-4 pm.** More details will follow. For specific questions or to RSVP, please contact Jessica Fosnaugh at jreguia1981@gmail.com.

SELF-ADVOCATES – The Self-Advocates will have a pizza and movie night at Turnstone on January 20! Rita is also planning a game night for February 17. More information will be forthcoming! Contact Rita Augustin at ritaauq1961@gmail.com with questions.

The first Self-Advocate / Friendship Club dance of the year will be held on **Friday, March 17 from 6:30 – 9 pm** at the Aboite Township Community Room. There will be no dance in February, as the Night to Shine Event, sponsored by County Line Church, will take place on February 10, and some of our Self-Advocates will be attending this event.

MARK YOUR CALENDARS – The DSANI Talent Show (featuring acts from the Self-Advocate and Friendship Clubs) will take place on **Friday, May 5** at the St. Joe Township Community Center!! This event is open for ANYONE TO ATTEND! Last year was the inaugural year for this event – and it was awesome!! For information about the dance or the talent show, please contact Kathy Meeks at kmmeeks@aol.com.

D.A.D.S. – The D.A.D.S. meet the fourth Thursday of each month, at various locations around the city. Feel free to email: dsani.dads.outreach@gmail.com



to inquire where the next gathering will take place. **The annual D.A.D.S. golf outing will take place on Friday, June 9!!** Save the date and gather a team! You'll enjoy a great day of golf and help support the D.A.D.S. group at the same time!

MOMS – There are events in the works for MOMS, and as soon as dates are confirmed, information will be emailed to you. If you have ideas for MOMS, please contact Jennifer Cordray at



Jennifer.cordray@sanofi.com.

GRANDPARENTS – The Grandparents group met at The Lodge on Huguenard Road earlier this month. Their next event is scheduled for **April 15 at 5 pm**, when the group will meet at GiGi's Playhouse for a tour. For more details, please contact Deb Clark at dclark@votawelectric.com.

OUTREACH - DSANI would like to extend its most sincere and heartfelt thanks to long-time Outreach Chair, Stacie Christle, for the outstanding job she has always done on behalf of DSANI. Due to more demanding family and work obligations, Stacie recently stepped down from the Outreach Chair position. Thank you, Stacie, for your devotion to DSANI and its new families!

Taking over the Outreach Chair responsibility is Annie Miller, also a DSANI mom. Annie and her husband, Jason, are the parents of soon-to-be five year old, Kate, and two-year old, Ben. Annie has some great ideas for Outreach, and we are so excited to welcome you aboard, Annie!

MEDICAL CORNER

Medically Speaking, by Stephanie Santoro, MD

Families often ask for suggestions about the best toys to buy to support their child's development. Often the best toy is the one that fits your child's developmental stage, abilities and interests. Some great rules of thumb when choosing toys:

- Is it safe and age appropriate?
- Is it durable?
- Can it be played with in more than one way?
- Does it appeal to several senses?
- Can it be used in more than one position?
- Does it involve the use of both hands?
- Does it include moving parts, buttons or gears?
- Does it encourage activity and movement?
- Does it encourage thinking or solving problems?
- Does it promote communication and interaction?

Birth to 12 months

Balls and rattles are excellent for infants and can provide a variety of options for interactive play (passing, rolling or playing peek-a-boo).

Blocks are another great option which can be played with in a variety of ways and for many years (wooden, Lego or any kind).

Play gyms are great at providing visual stimuli which can be changed to keep a child interested.

Activity tables and cubes are great for little ones who are just beginning to pull to stand or starting to cruise. Activities on the top provide an added fine motor skill to master.

1 to 3 years

Interactive toys like a classic jack-in-the-box can teach concepts like cause and effect to young toddlers.

Fine motor skills and problem solving are developed with stackers and shape sorters.

Balls are a great option for this age as well – kids love to chase, throw and kick them as they develop gross motor skills. Interactive balls have the added benefit of teaching letters and numbers.

Tunnels and tents are fun for gross motor development and can be used creatively.

3 to 5 years

Activity mats, like Aquadoodle, are useful to begin working on handwriting and hand-eye coordination.

Games like the Super Sorting Pie allow little ones to continue to develop fine motor skills as well as to play in an interactive way and to learn turn-taking. Cooperative games, like Hoot Owl Hoot, teach problem solving and instill a sense of teamwork.

Tricycles and ride-on toys are a great option for improving gross motor skills, coordination and balance. Look for one that adjusts to your child.

Dress-up clothes, playhouses, kitchen sets and workbenches can develop pretend play as well as cooperation and negotiation when playing with others. Play store toys (cash registers and shopping carts) are great to use in conjunction with play kitchens to encourage communication and language.

Cars, trucks, trains and city toys allow for pretend play and elicit speech.

5 to 7 years

Play-Doh craft kits and models are sure to be a hit in this age group. Kids are encouraged to play freely while working on fine motor skills and given opportunity for creativity.

Pretend play becomes more advanced as kids develop interests in dolls, ponies, action heroes or other figurines. Some houses or stables have the added benefit of latches and small doors that help improve dexterity through play.

A simple tool set is great for hand-eye coordination, fine motor skills, and can provide opportunities for speech and language learning as well.

Science kits and cooking kits are good choices to promote thinking and problem solving.

8 to 11 years

Problem solving, logic and critical thinking skills can be developed in older kids through board games like Apples to Apples Jr. or Hedbanz. Pictionary is likely to lead to memorable family moments.

More advanced building kits and puzzles are popular as older kids begin to develop greater attention to detail, require them to follow multi-step directions and develop confidence. STEM toys focusing on coding or electrics may develop critical thinking skills too.

12 to 14 years

For tweens and teens, elaborating on a child's interest may be the best way to go. Is your child a fashionista? Consider a sewing machine or knitting kit. Budding scientists may be interested in a microscope or crystal growing kit. Artists may appreciate art supplies or advanced art kits.

Ultimately, the best toys are those that teach our children a new skill or concept and are FUN! As parents, you know your child best and may be able to pinpoint those skills which are emerging. And, always remember to ask yourself, is it worth the costs? Some of the best "toys" are items you already have at home that don't cost much. Consider whether you can substitute the toy that you are considering buying with something you already have at home. For example, colorful plastic cups can be stacked and sorted, and plastic containers and lids can become puzzles. You can play peek-a-boo with a dish towel, turn a coffee can into a shape sorter or a bank, or use chocolate pudding poured over tinfoil in a cookie sheet as finger paint. Lastly, when in doubt, a book is always a great gift that can promote interaction, discussion and imagination!

Some information from AOTA:
communicationskillsforlife.files.wordpress.com/2012/11/aotaplaylist.pdf

Our thanks to Dr. Santoro, for permission to reprint this article. Thank you also to DSACO's "Keeping Up" publication for their cooperation in reprinting the article.

AREA NEWS OF INTEREST

TURNSTONE

Turnstone has begun recreational programming for people with intellectual and developmental disabilities! There are a number of wide-ranging opportunities in which your loved one can be involved. Some programs are offered free of charge, and others for a minimal fee. First quarter programs, for ages 13+ include basketball, game night, floor hockey, a walking program, girl's night out, curling, indoor cycling, a health & nutrition series, creative movement and even a spring dance! For more information and age requirements, contact: Rio James at Turnstone, by phone at (260) 969-7678 or by email at: rio@turnstone.org. DSANI also emails out the Turnstone quarterly schedule of classes as well.

ARTS UNITED CENTER

We are very encouraged to know that the Arts United Center, in Fort Wayne, is taking the lead in the arts community to make many of their facilities and spaces accessible to a variety of individuals with disabilities! They have formed a committee and have also retained an architectural firm to look at the challenges the disability community faces, whether that be an intellectual, physical or other disability, when patronizing an arts event. They hope to embark on a capital campaign to renovate the Arts United Center to make it accessible to all!

RIVERFRONT DEVELOPMENT

In addition, the task force taking the lead on the downtown Riverfront project, is actively seeking input from leaders in the disabilities community. They are committed to making this new gathering place accessible to all!

DOWN SYNDROME ORGANIZATION WEBSITES

National Down Syndrome Society – www.ndss.org

National Down Syndrome Congress – www.ndsccenter.org

DS-Connect: The Down Syndrome Registry – www.dsconnect.nih.gov

LuMind Research Down Syndrome Foundation – www.lumindfoundation.org

Global Down Syndrome Foundation – www.globaldownsyndrome.org

2017 DSANI MEMBERSHIP CAMPAIGN

2017 Membership renewal forms will be emailed and sent to DSANI families in March. Please remember, we have no way of knowing if your email address, mailing address, phone number, etc. changes unless we have an updated form on file.

While we ask that the membership fee is paid each year, this will be critical once the improved website is up and running. There will be sections of the website that will require members to have a password in order to gain access. The password will only be given out if you are a member in good standing. You must also be a current

member to be able to register your loved one for Camp Red Cedar in the summer.

If you have information you think would be helpful to families, and should be included in the newsletter, please forward it to the DSANI office at: administrator@dsani.org

NEWSLETTER NAMING CONTEST!

Do you have a **GREAT** idea for a name for the newsletter? If so – we want to hear from you!! **Naming submissions should be returned to the DSANI office by February 28, 2017!** The winner will be awarded a \$50 VISA gift card! Good luck!

2016 HOLIDAY PARTY RECAP

Over 225 DSANI members enjoyed the Holiday Party in early December. With the help of many community volunteers and the generosity of local merchants, a great day was had by all who attended! Our special thanks, as well, to DSANI D.A.D.S., Santa & Mrs. Claus, Dawn Staton, Dynamic Sound Entertainment, Judie Brough, Lauren Stough, Elijah Mettert, The Taylor Family, Joshua Schmidt, The Fort Wayne Rugby Club, Dan & Char Sery and volunteers from Manchester Pharmacy School, Norwell High School, Snider High School, Trine DPT Program and Huntington OT Program. We hope to see even more families at next year's party!



STAY CONNECTED TO DSANI!

Mailing address: PO Box 13611, Fort Wayne, IN 46865

Physical address: 3320 N. Clinton Street – Fort Wayne (Turnstone)

Phone: (260) 471-9964

Email: administrator@dsani.org

Facebook: Down Syndrome Association of Northeast Indiana

Twitter: @DSANI4U



Fundraising

In Honor of: Down Syndrome Association of Northeast Indiana

Monday February 20th , 2017 4pm – 9pm



10% Donation Night

Down Syndrome Association of Northeast Indiana

will receive 10% of total food purchases when you present this flyer to
your server.

Come join Texas Roadhouse and DSANI to enhance the lives of the
families affected by Down syndrome



260-416-0919

710 W. Washington Ctr rd

Fort Wayne, IN 46825

