

## I. A LETTER FROM THE EDITORS

### Greetings from The MIRROR editing staff at the Dup15q Alliance!

We hope that you are enjoying the beautiful summer months with your family.

We are very excited to report that the Alliance continues to increase awareness of Dup15q Syndrome, provide needed support to families, and promote research that is directly related to improving the lives of individuals living with Dup15q.

Since the way the world communicates is constantly changing, the Dup15q Alliance is "going with the flow", as they say, in the way that we reach out to our community. We have increased the frequency of our electronic newsletters to bi-monthly, and we hope that you find these mini-newsletters informative and engaging. We took a step back to think about the MIRROR's objective and our newest Board Member and new MIRROR editor, Julia Jordanich, had the wonderful idea of using the MIRROR for articles to investigate "hot topics". In this edition you will find "Clinical Care Steps for Seizure Onset and Beyond": an article written in direct response to many families' need to navigate seizure onset. Also included are helpful articles with regard to health and therapeutic interventions, as well as important updates regarding the Alliance's membership, partnerships, funded research publications, and Q-usader fundraising progress. This edition further includes information regarding past and upcoming Dup15q-related conferences and other important events. Lastly, we believe that the greatest source of strength is our wonderful families. Their stories are our stories, so don't miss Lisa Wesel's article titled "The Belle of the Ball"!

Thank you so much for all of your wonderful support!

Julia Jordanich, Naka King, Lauren Weissberg, and Vanessa Vogel-Farley

### The Dup15q Alliance --Advocating For You

Dup15q Alliance Membership Reaches 1,348 in 2018

In 2018, membership in the Dup15q Alliance has grown to over 1,300+ living with Dup15q in the United States and 40 other countries. This figure includes both adults and children, and reflects a 15% yearly increase over the last 3 years. There are 750+ members with Dup15q in the United States, as well as 420+ members in the Alliance's international community. As our community grows, we want to enable families to connect with other families that are closest to where you live. In the coming months, we will be launching a "directory" of sorts where you can see the location of families closest to you by postal code. In order to respect privacy, direct contact informant will need to be requested via the administration. If you would like to locate members in your state or country, please email Ava at admin@dup15q.org.



## II. DUP15q Q-NNECTIONS

### What is our Executive Director up to?

Ever wonder what Executive Director Vanessa Vogel-Farley is doing to further the Dup15q Alliance goals in research and outreach? Here's a quick summary of events that she has attended over the last 10 months:



- September 13, 2017 (Irvine, CA): Vanessa represented the Dup15q Alliance at the 2017 Global Genes Rare Patient Advocacy Summit and discussed how the Dup15q Alliance engages the next generation of researchers and clinicians.
- October 3, 2017 (Boston, MA): Vanessa, and Dup15q parents Jaqueline Hadaya, & Len and Joanne Poore attended the Disorder: Rare Disease Film Festival in Boston, MA. This is a new event that shows primarily documentaries from around the world that focus on living with a rare disease. The documentary "Believe: Living with Dup15q Syndrome" was screened followed by a question and answer with the Dup15q Alliance panel. While there, the group was interviewed for the CheckRare.
- October 25, 2017 (New York, NY): Vanessa attended The Patient Registry Workshop meeting hosted by the Simons Foundation in New York City along with representatives from the Autism Science Foundation, the IAN Project, Interactive Autism Network, Phelan-McDermid Syndrome Foundation, Simons Foundation, Rett Syndrome Research Trust, Geisinger Health System, UCLA and UCSF to work on helping autism registries to communicate with one another, and to further determine what researchers need from these registries.



- December 1, 2017 (Washington DC): Vanessa attended the American Epilepsy Society meeting. While there, she represented the Dup15q Alliance at the Epilepsy Leadership Council meeting as well as at the Infantile Spasms Action Network meeting to discuss seizures, clinical care and research as part of Infantile Spasms Awareness Week.
- January 20th-21st, 2018 (Highland Park, IL). The administrative staff and 2 board members joined Vanessa for an Administrative Retreat in order to plan out the upcoming year and administrative/fundraising priorities.
- January 23rd-24th, 2018 (Los Angeles, CA): Dup15q Alliance research/science brainstorm. Board members Mike Porath, Guy Calvert, Professional Advisory Board member, Shafali Jeste and Vanessa compiled a summary of Dup15q Alliance funded proposals, grants, and special projects to date, the resulting publications, and spin off funding. The purpose of the summary was to update the strategic vision for the research arm of the Dup15q Alliance, and to create community directed research priorities for the organization's overall strategic plan.
- March 20th-21st, 2018 (Columbus, OH): Vanessa attended the Epilepsy Learning Healthcare System Collaborative Learning Event. This event brought together representatives from groups committed to build a community of people with epilepsy, caregivers, healthcare providers, researchers, and other stakeholders who work together to reduce seizures and improve outcomes for all people with epilepsy through a learning healthcare system (LHS). The goal is to create a cyclical process in which clinical data is collected at the point of care, then analyzed, and rapidly disseminated to change practice and improve outcomes. The initial focus is on quality, given the American Academy of Neurology Child Neurology Quality Measures (which include several epilepsy specific measures), and the recent revision of Epilepsy Quality Measures. The long-term vision is to facilitate research in quality, health services, epidemiology, comparative effectiveness, and evaluation of novel therapies to improve care across the entire spectrum of epilepsy severity. Healthcare providers, researchers, and individuals with epilepsy and their families are all equal stakeholders in designing and implementing the learning health network.
- April 25th-27th, 2018 (Oxon Hill, MD): Vanessa attended the World Orphan Drug Congress USA focuses on the most pressing challenges and opportunities to bring rare disease therapies to patients faster. Bringing together a global gathering of 1,200 leaders in orphan drugs from 50 countries, World Orphan Drug Congress USA will feature over 135 presentations covering all aspects of orphan drug development and rare disease research.
- June 14th-16th (Alexandria, VA): Vanessa attended the PAME Conference which provides a unique forum for clinicians, researchers, public health officials, patients, and families affected by epilepsy to come together in an effort to better understand, address, and ultimately reduce mortality in epilepsy. While in DC, Vanessa further participated in Capital Hill Visits to inform governmental representatives of the importance of state and federal support of research and medical care related to epilepsy.



### III. DUP15q PARTNERSHIPS



The Dup15q Alliance has partnered with The brain recovery project which is one of our partners with ISAN Network. This project provides guides, information, and programs for parents considering or whose children have had brain surgery to stop seizures. In March of 2018, Dreams for Danny Surgical Evaluation Travel Scholarship was launched to help families afford travel and lodging associated with an epilepsy surgery consultation. Funded by a very generous donation from the Abel family in honor of their son, Danny, this new program provides up to \$1,000 in approved travel funds for scholarship awardees. Visit [brainrecoveryproject.org](http://brainrecoveryproject.org) to apply.



The Dup15q Alliance has partnered with The Tuberous Sclerosis Alliance and 7 other rare epilepsy organizations to request a CME (Continuing Medical Education) from the Child Neurology Working Group. The Child Neurology working group was formed with a goal of coordinating our efforts to assure that the professional needs of child neurologists are supported.

Together we determined that developmental and behavioral medicine represents a large gap in care. After reviewing the needs, it was identified the following overlapping areas that the CME program would potentially address:

1. Early Intervention- standards and methods for monitoring epilepsy/infantile spasms, impact of early intervention on neurocognitive outcomes, and barriers to access recommended therapies.
2. Behavior - methods for improving social interactions, communications skills, aggression and appropriate available resources.
3. Neurology throughout the lifetime - long-term impacts of seizures on developmental stages, learning/memory process, sleep cycles and anxiety/depression disorders; transition of care from pediatric to adult physicians.

## The MIGHTY

The Dup15a Alliance is thrilled to announce our partnership with The Mighty. The Mighty was founded by our very own Mike and Sarah Porath, whose daughter Annabel is living with Dup15q Syndrome. This new partnership will bring our resources in front of The Mighty's wide-reaching readership. We will now have a growing home page on The Mighty and appear in many stories on the site.

The Mighty is a story-based health community focused on improving the lives of people facing disease, disorder, mental illness and disability. More than half of Americans are facing serious health conditions or medical issues. The Mighty publishes real stories about real people facing real challenges.

The Dup15q Alliance is dedicated to helping people with Dup15q Syndrome in their lives. With this partnership, we'll be able to help even more people.

The Dup15q home page on The Mighty is located at <https://themighty.com/dup-15q-syndrome/>. We also encourage you to submit a story to The Mighty and make your voice heard.

The Dup15q Alliance is excited to announce we have established a partnership with Infantile Spasms Action Network. A collaborative network of 20+ national and international entities dedicated to raising awareness for IS.



The Dup15q community is on the forefront of driving research and awareness to make real progress in rare disease. Our own Mike Porath, Dup15q Alliance Board member and Founder/CEO of The Mighty, is joining 14 others from Shire, Microsoft, and EURORDIS to form Global Commission to End the Diagnostic Odyssey for children with Rare Disease.

This is a multidisciplinary group of experts with the creativity, technological expertise, and commitment required to make a major difference in the lives of millions of children and their families. The Global Commission will develop an actionable road map to help the rare disease field to shorten the multi-year diagnostic journey, which is considered a key to a longer, healthier life.

Today, too many children around the world are suffering from rare diseases that remain undiagnosed as parents struggle to navigate complex health systems and receive multiple misdiagnoses. Eliminating barriers to an accurate and early diagnosis can lead to faster treatment, with life-altering results.

Learn more at [globalrareiseasecommission.com](http://globalrareiseasecommission.com)

**DUP15q ALLIANCE - 9TH INTERNATIONAL FAMILY CONFERENCE, JULY 23-26, 2017**

**IV. DUP15q CONFERENCE INFORMATION**

**DUP15q ALLIANCE SCIENTIFIC SYMPOSIUM, JULY 26-27, 2017**



**Seminar Videos From the Dup15q Alliance 9th International Family Conference Are Still Available for Viewing!**

On July 23 to July 26, 2017, the Dup15q Alliance hosted its highest-ever attended 9th International Family Conference - Navigating the Future -in Redondo Beach, CA. During this 3-day conference, 381 attendees selected from a total of 27 seminars that addressed a multitude of issues facing our families living with Dup15q. Currently, 20 of these seminars are available on our website, thanks to Monica and Noah Kadner. We encourage you to review the seminars that you attended or to watch them for the first time!

Visit <https://www.dup15q.org/events/family-conferences/navigating-the-future-2017/navigating-the-future-2017-conference-schedule/>

**Seminar Videos From the Dup15q Alliance Scientific Symposium Are Available For Viewing!**

On July 27-27, 2017, the Dup15q Alliance hosted its Scientific Symposium at the Luskin Conference Center at the UCLA campus in Los Angeles, CA. During this 2-day conference, researchers and clinicians from all over the US and world presented the latest research and clinical care for Dup15q syndrome. Of the 28 presentations that occurred over the 2-day period, 23 are available. This provides an excellent opportunity to review the seminars that you attended or to watch them for the first time!

Visit <https://www.dup15q.org/events/scientific-conferences/2017-dup15q-alliance-scientific-symposium/>



**2019 Dup15q Alliance International Family Conference**

**Houston, Texas from July 18th-20th, 2019.**

**Stay tuned for more details**

## The Dup15q Alliance is Excited to Announce Four New Research Publications

We are excited to provide you with the links to four recent research articles in 2018 that are directly related to Dup15q. All four are now available on our website for your review at <https://www.dup15q.org/research/published-articles/>.

**The Autism Protein Ube3A/E6AP Remodels Neuronal Dendritic Arborization via Caspase-Dependent Microtubule Destabilization.** Authors: Natasha Khatri, James P. Gilbert, Yuda Huo, Roozhin Sharafliari, Michael Nee, Hui Qiao and Heng-Ye Man. January 18, 2018.

**Significant Transcriptional Changes in 15q Duplication But Not Angelman Syndrome Deletion Stem Cell-Derived Neurons.** Authors: Nora Urraca, Kevin Hope, A. Kaitlyn Victor, T. Grant Belgard, Rawaha Memon, Sarita Goorha, Colleen Valdez, Quynh T. Tran, Silvia Sanchez, Juanma Ramirez, Martin Donaldson, Dave Bridges, and Lawrence T. Reiter. January 27, 2018.

**Cardiac Arrhythmia and Neuroexcitability Gene Variants in Resected Brain Tissue from Patients with Sudden Unexpected Death in Epilepsy (SUDEP).** Authors: Daniel Friedman, Kasthuri Kannan, Arline Faustin, Seema Shroff, Cheddhi Thomas, Adriana Heguy, Jonathan Serrano, Matija Snuderl & Orrin Devinsky. March 27, 2018.

**Uncovering True Cellular Phenotypes: Using Induced Pluripotent Stem Cell-Derived Neurons to Study Early Insults in Neurodevelopmental Disorders**  
Authors: James J. Fink and Eric S. Levine  
April 16, 2018

## The Rare Epilepsy Network Registry Needs You

The Dup15q Alliance is excited to announce that the Rare Epilepsy Network (REN) Registry is open for enrollment! The REN is a patient-powered and patient-centered research network that will expedite research into the rare epilepsies.

The REN is led by the Epilepsy Foundation in partnership with 10 rare epilepsy organizations, including Dup15q Alliance, Columbia University, New York University and RTI International. Dup15q Alliance is hoping to recruit at least 100 people with chromosome 15q11.2-13.1 duplication (Dup15q Syndrome) into the REN, and we need your help to make this happen. There are no exclusion criteria, as long as, the person affected by Dup15q Syndrome has had one or more seizures.

If you are a parent or legal guardian of a person with Dup15q syndrome, please consider participation in this important research project. Enrollment in the Registry is simple. You will be asked to fill out a survey about the child/affected person with Dup15q Syndrome which asks about their diagnosis, seizures, treatment, development and medical history. There is also a section that asks about your quality of life and the impact that epilepsy has had on your family. The more information you provide in completing the questions, the more valuable your data will be for research. If you have a list of seizure drugs that were EVER taken, this may help you in completing the section about treatment. To learn more about the Registry or to begin the enrollment process, please visit the REN website at <http://REN.rti.org>.



## V. RESEARCH

## Dup15q Alliance Awarded Child Neurology Foundation Grant

In November 2017, the Dup15q Alliance was awarded a grant in the amount of \$5000 from the Child Neurology Foundation to look at the prevalence of infantile spasms in Dup15q syndrome and to supply educational materials to physicians to encourage genetic testing in the presence of infantile spasms. Seizures occur in an estimated 65% of those with dup15q syndrome, with many parents reporting suspected seizures/infantile spasms in infancy much earlier than the formal diagnosis of Dup15q syndrome.

Presence of infantile spasms is one of the main reasons that a patient under 12 months of age undergoes the genetic testing that reveals dup15q syndrome. More recently dup15q syndrome patients are being identified younger and younger. This is in part due to the standard of care that includes genetic testing in the presence of hypotonia, infantile spasms and/or failure to thrive."



# VI. Clinical Care Steps for Seizure Onset and Beyond

By: Dr. Jane Kim, MD

## WHAT IS A SEIZURE?

A seizure is abnormal electrical activity in the brain. It is sometimes described as an electrical storm. There are many different seizure types and they can each look very different. For a description of the seizure types, please check out our webpage: <https://www.dup15q.org/treatment/seizures/>

## HOW COMMON ARE SEIZURES IN DUP15Q SYNDROME?

More than 50% of individuals with dup15q syndrome develop epilepsy in their lifetime. Seizures most often begin between age 6 months and 9 years.

## WHAT SHOULD I DO IF MY CHILD HAS A SEIZURE?

Make sure they are in a safe place where they are not in danger of getting hurt. If possible, lie them down on their side. Do not put anything in their mouth. Look at a clock and determine the time when the seizure started. If the seizure lasts more than 5 minutes, call 911. Otherwise, keep track of how long the seizure lasts. Afterwards, it is common for the person to be tired and confused.

## WHAT ARE THE NEXT STEPS AFTER A FIRST TIME SEIZURE?

For first time seizure, often times the ER is the first stop. After the ER visit, a referral should be made to a neurologist, if you don't already have one. Ideally, an appointment would be made with a neurologist within 1-2 weeks, but the wait time can sometimes be long, depending on your region. If you live near a Dup15q clinic, you may want to be seen by a clinician familiar with dup15q syndrome: <https://www.dup15q.org/treatment/dup15q-clinics/>



An electroencephalogram (EEG) should be ordered. The decision to start a daily seizure medication after a first seizure is up to you and your neurologist. Sometimes the EEG results are used to guide the decision. Other times, a daily seizure medication may be started after the first seizure given the high prevalence of seizures in the dup15q population.

The first choice of medication will depend on the seizure type. Clinicians may want to refer to our website for more information about seizure treatment: <https://www.dup15q.org/treatment/seizures/epilepsy-treatment/>

## WHAT ARE SOME IMPORTANT THINGS TO DO AFTERWARDS?

Keeping a seizure log is helpful to keep track of how often the seizures occur and if there are any patterns. You can keep a pen/paper log on a calendar or there are several online resources, such as seizure tracker, my seizure diary, etc. You should be in touch with your neurologist if the seizures continue despite being on medication. At that point, the medication may need to be changed to a different one, or a second medication may be added on.

## WHAT ABOUT FOLLOW UP VISITS AND STUDIES?

Follow up visits with a neurologist are variable. If seizures remain under good control, an annual visit may be sufficient. If seizures remain uncontrolled, there will likely be continued follow up throughout the year with office visits, telephone calls, etc. The Dup15q Alliance clinics working group recommends an annual EEG with additional 24 hour EEG monitoring as needed.

## WHAT ARE RESCUE MEDICATIONS?

Your neurologist may prescribe a rescue medication to help stop a prolonged seizure. Most rescue medications are in the benzodiazepene class of medication. Some common ones are diazepam (Diastat, Valium), lorazepam (Ativan), midazolam (Versed), etc. Your neurologist should give you directions on when to use a rescue medication but is usually indicated for a seizure lasting more than several minutes or several seizures in a row. It does not necessarily need to be used for every seizure.



## VII. HEALTH & THERAPEUTIC INTERVENTIONS

### Using ABA to Learn Necessary Skills and Curb Difficult Behaviors - A Dup15Q Parent's Perspective By: Julia Jordanich



(Using ABA to teach Nat the use of PECS)

I'll be honest. When our developmental pediatrician first suggested full-time Applied Behavior Analysis ("ABA") therapy for our then 2-year daughter with Dup15q syndrome, I was very opposed to the idea. I wanted my child at home with me and not in an ABA center during the day. Also, I had read various negative reviews about ABA by parents who said it lacked creativity and would, as someone had written, "force my child to do various mindless actions over and over again."

As I investigated further, however, I learned a lot about the positive aspects of ABA. As I watched ABA in action at a local center, I realized it could actually help my daughter to learn things that, at that point, seemed implausible. My husband and I therefore decided to try out it out full time. To this day, we have never regretted this decision.

I should point out that I'm a lawyer who practices in the area of foster care and guardianships. I have no expertise with regard to education, special education, various therapies, etc. Even though I can generally comprehend dense legal articles, I couldn't, for the life of me, understand ABA when I first began to research it. I vividly recall reading articles about it and feeling none the wiser. They all seemed to provide a broad definition of ABA but did not offer an explanation of what it actually entails. Here's one of my favorite definitions listed on the Center for Autism website:

*Behavior Analysis is the scientific study of behavior. Applied Behavior Analysis (ABA) is the application of the principles of learning and motivation from Behavior Analysis, and the procedures and technology derived from those principles, to the solution of problems of social significance. Many decades of research have validated treatments based on ABA. ("ABA Resources: What Is ABA?" Center for Autism and Related Disorders, [www.centerforautism.com/aba-therapy.aspx](http://www.centerforautism.com/aba-therapy.aspx).)*

I mean, what??

Now that our daughter has been participating in ABA therapy for 3 years, I feel a bit more prepared to explain what it is and how it benefits our Dup15q kids. In a nutshell, ABA therapy focuses on principles and techniques to bring about positive change in behavior. Positive reinforcement is one of those principles, and appears to be one which is frequently used. Why is this the case? Simply put, a behavior is likely to be repeated if it is followed by a reward.

Still confused? Here are some examples where ABA therapists, using positive reinforcement, have successfully taught our daughter some very valuable skills.

At 2 years of age, our daughter was not taking independent steps to walk on her own. During her therapy sessions, two ABA therapists stood approximately 7 feet apart, each holding a preferred item that she wanted. As soon as she would take just one step on her own towards a therapist, she would immediately get the item. Eventually, she had to take two steps to get the item. Eventually it had to be three steps, and so forth. In 2 weeks time, she walked completely independently.

At 3 years of age, our daughter continued to be nonverbal and had no way to communicate. Within 2 months of full time ABA therapy, she learned to use the Picture Exchange Communication System ("PECS") to communicate her desire for a preferred item. In this case, it was a video. Initially, she had to touch the PEC to get the video. Eventually, she had to pick up the PEC to get it. After that, she had to pick up the PEC and give it to her therapist to get the video. Over time, she has learned to transfer this skill to our home. She now uses PECS to request food, drink, videos, toys, and even some actions like reading, tickling and hugs. Since she continues to be nonverbal, this is an essential skill that she continues to work on at ABA center to this day. We are hoping that she will eventually communicate about things she observes or feels as well. (continued)



## VIII. CHROMOSOME Q-USADERS

Chromosome Q-usaders are Dup15q Alliance members who have gone above and beyond to raise funds and awareness about Dup15q Syndrome. All of these fundraisers directly support the Dup15q Alliance's mission of encouraging personal philanthropy that helps underwrite research, offer potential treatments, and provide support to all Dup15q Alliance families. Thanks to ALL of you for fighting to give our children a better tomorrow!

### Thank you for Believing and Achieving! 2017/2018 Q-usaders

#### **Achieve Q-usader - raised \$10,000+**

Aiisha Sablan Ramiro  
Lauren Weissberg  
Colleen Lowell

#### **Dream Q-usader - raised \$7,500-\$9,999**

Cortney Manning  
Ruth Kross  
Ivonne Ruiz Feterman  
Christine Key Benitez

#### **Hope Q-usader - raised \$5,000-\$7,499**

Tina DeLorenzo  
Christine Hemingway  
James Borden

#### **Super Duper Q-usader - raised \$2,500-\$4,999**

Mike Porath  
Rob and Fabiana Roman  
Krissa Harris  
Naka King  
Ember Burke

#### **Duper Q-usader - raised \$1,000-\$2,500**

Adrienne Felterman  
Aivry Zamora

#### **Advocate Q-usader - raised \$500-\$999**

Heather Sheldon  
Jenn Kelly  
Laura Barteu Stark  
Corrine Murphy  
Alan Lundgren  
Sarah Champman

#### **Believe Q-usader - raised \$250-\$499**

Stefanie Lebeilly  
Lacey Berger  
Stephanie Claxton  
Emmy Lou Allen



Together We Believe **DUP15q** Together We Achieve  
ALLIANCE



## The Belle of the Ball

by Lisa Wesel, Bowdoinham, Maine

I'm on a flight to Colorado for my niece's wedding with Lidia by my side, her beloved, ever-present teddy bear clutched tightly on her lap. She is absorbed in her word search, dutifully circling the words she's found and checking them off the list with her backwards check-marks. My carry-on is weighted down with crayons and coloring books and other things to keep her occupied.

It's not how I pictured life with a 20-year-old.

Lidia has never proven to be what anyone pictured. She was big and beautiful and perfectly healthy at birth, with dark brown eyes, a full head of black hair and a stubborn streak that would test both me and her father, but would end up being her staunchest ally.

Lidia never crawled, only rolled. Her eyes crossed when she was a few months old. She failed to meet one milestone after another. Her speech was odd, her balance wonky. At age four, after an MRI, she was diagnosed with a delayed growth of myelin on her brain. We were told that it would be very difficult for her to read, that her pragmatic speech may never develop. She fell down almost every time she walked, so bike riding was out of the question. And executive function was practically non-existent.

But we refused to listen, and Lidia never stopped trying. We were lucky to find truly gifted PTs, OTs and speech therapists, not to mention the public school teachers who changed her life. And Lidia worked very, very hard. Her life was filled with people struggling to teach her what other kids pick up naturally - how to walk, how to run, how to have a conversation that passes between two people who take turns talking.

Lidia defied the odds. She learned to read, and loves historical fiction. She walks with her own sort of rhythm, and still falls down when she's over-tired, but she did learn how to ride a bike. She got a job volunteering at a local nursing home, delivering mail to the residents. And she never. Stops. Talking.

But at 15, she suffered a massive grand mal seizure, the first of many, followed by the Russian roulette of trying to find the right medications. Her development went into a tailspin. She lost over a year of education while her teachers struggled just to maintain the status quo. That's when she was diagnosed with Dup15q.

Lidia has come back from that, too. She was hired to work part-time in the kitchen at the nursing home - a real paid job. And she and her younger sister, Anita, have graduated from high school together last June. At the senior awards ceremony, Lidia was given the "Phoenix Award," for rising above her many hardships.

Anita asked me once, years ago, after a particularly trying day, if I could make Lidia "normal," would I do that? That was harder to answer than one would think. I certainly want her life to be easier, and I would like for her, just sometimes, to stop talking! But if we took away Lidia's disability, would we also lose the wonderful qualities that make her who she is? The goofy sense of humor that inspires her teachers to show up for work every day? The smile that the nursing home residents look forward to seeing? The way she has made me, Anita and their father more patient and compassionate people?

At the wedding, Lidia is the belle of the ball. While my "typical" 18-year-old and I struggle to navigate the crowd (we call ourselves "mingling-impaired"), Lidia makes the rounds. She hugs and kisses her loving cousins and introduces herself to everyone she doesn't know.



## IX. DUPER FAMILY STORIES

On the long flight home, Lidia and I are sitting one row in front of a baby who is screaming relentlessly for the teddy bear her mother packed in the suitcase. Lidia tries to ignore the baby, but she can't stand to hear her cry. She gives her own cherished teddy bear a hug, unbuckles her seat belt and turns around to face the baby's mother.

"Would she like to hold my teddy bear? Just for the flight?"

No, I wouldn't change Lidia. Not for anything.





**Colby Mosely**

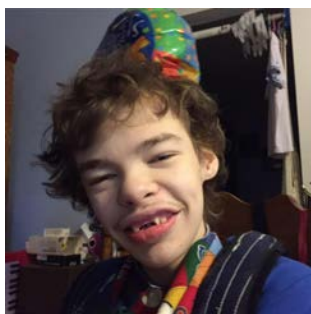
**Oct. 15, 2001 - Oct. 05, 2017**

Our beloved Colby was born on October 15 2001. Colby touched the lives of the people who had the privilege of knowing him. He was so happy and his smile would melt your heart.

Even though he could not speak his eyes and expression would speak to you loud and clear. Colby was so handsome and stylish. He loved to dress and model for us

Colby loved to swim and take long walks. His best pastime was stealing ones food when you were not looking

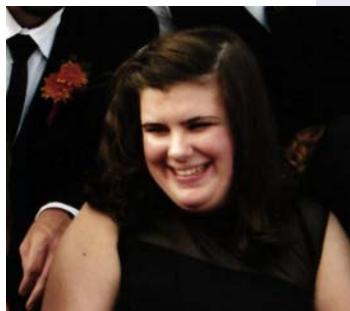
With his courage he led us to believe that everyday is a blessing, a great gift that should not be taken for granted. His beauty and smile will be cherished in our hearts like treasures of gold. He will remain in our hearts and souls. We will never let go of his precious memories. Rest In Peace until we meet again Love mommy and daddy♥



**Evan MacKey**

**Sept. 28, 1994-Jun. 13, 2017**

Evan Tyler Mackey, 22, of Rustburg, Va. passed away on Tuesday, June 13, 2017, at Hendricks Regional Health, Danville, Indiana. He was born on September 28, 1994, in Lynchburg, Virginia. Evan graduated from Laurel Regional School with the class of 2016. He loved his family, spending time with his siblings and his Papaw, listening to music, traveling and going to the beach. He was a very happy person, loved by all. He will be greatly missed. He is survived by his parents, father, Dewayne (Nancy) Mackey, Appomattox, Va.; mother, Jamie Mackey, Rustburg, Va.; siblings, Ethan and Elizabeth Mackey, Rustburg, Va.; grandparents, Edmun (Brenda) Mackey, Rustburg, Va. and William Dickerson, Roachdale; and cousins, Jessica and Alex Mackey. He was preceded in death by his grandmother, Jane Dickerson.



**Colleen Bruton**

**1990- Aug. 11, 2017**

Colleen M. Bruton, 27, of Springfield, PA passed away on August 11, 2017.

For all who have asked--here is Sean's "Words of Remembrance" for Colleen ♥

Here Goes Nothing.

The wonderful Wizard of Oz once said..."A heart is not judged by how much you love, but by how much you are loved by others."

Colleen's journey down the yellow brick road began 27 years ago when my family welcomed this beautiful and special girl into our world.

We had already experienced our own big TWISTER with Patrick...And along came Col filling that void in so many of our hearts.

Much like Dorothy with her braids and love for doggies, bringing joy and excitement to Munchkin Land - Was Colleen - bringing even more joy and excitement to the Bruton's, Craig's and everyone in between.

Dorothy was in search of 4 things...BRAINS, COURAGE, HEART and HOME. These are 4 things that Colleen has instilled in all of us.

For all of our BRAINS that are questioning how something like this could happen to someone like Col... May we hold onto the Happy Memories...they are what will get us through.

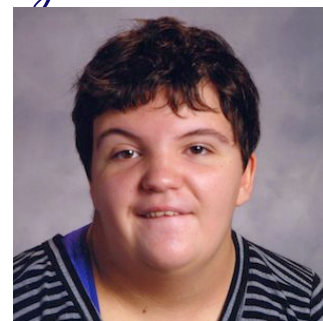
- The many Rides on the TramCar at the Boardwalk in Wildwood.
  - Her Love of Horses and getting to ride at Thorncroft.
  - The Hundreds of Dolls...each with their own special name. Some Big Lots Brand, Some Actual Mattel Brand.
  - The Pure excitement of Sour Cream on Nachos and her love of Wings thanks to Brian And Jenna.
  - Our Numerous Mountain trips and Train Rides at Knoebels.
  - Her laughter and joy watching her 4 nieces get in trouble with Gigi and Pops...well let's face it...mostly just Abby and Evy.
  - And The bizarre fascination with Lawrence Welk, and the drama of COPS...BAD BOYS, BAD BOYS.
- For all of us searching for COURAGE. This will take time. Courage doesn't always ROAR...Sometimes Courage is a quiet voice saying - I will try again tomorrow.
- The Wizard also said, "HEARTS will never be practical until they can be made unbreakable." For all of our HEARTS that are broken, may they be filled with the Love that Col always gave.

So Colleen...as you click your heels to go HOME...with all who went before you... May you enjoy Cocktail Hours with Nana and Pop-Pop, while watching Wheel of Fortune with Pop-Pop and Mom-Mom. And be sure to Celebrate St. Patty's Day...EVERYDAY...with our beloved Patrick. May your troubles melt like lemon drops way above chimney tops...and be sure to always remember... "I've Heard it said that people come into our lives for a reason...bringing something we must learn... and we are led to those, who help us grow...if we help them in return." Who can say if We've been changed for the better? ...but because We knew you... We've been changed for Good." Your Face is still at the Heart of Our Everything....We love you Col!!!!!!!

## X. IN REMEMBRANCE

*Your life was a blessing,  
Your memory a treasure*

*You are loved beyond words and missed beyond measure*



**Hayley Plate**

**Nov. 8, 1999 - Mar. 23, 2018**

Hayley Ann Plate, 18, of Hilbert, WI, passed away on March 23, 2018, at her home in Hilbert. She was born November 8, 1999, in Appleton. She was the daughter of Kevin and Laurie (Mueller) Plate.

Hayley knew how to have a good time. She enjoyed watching Dora & Baby Jaguar, as well as Toy Story and Clifford. You could find her on her Kindle or taking selfies whenever she wasn't busy listening to music, dancing, and singing with her dad. She was also fascinated with numbers, clocks, and watches.

Her giggle was infectious and you could hear it throughout the house. She liked drinking soda and baking cookies. Her sweet tooth came outside, too. She was a pro at making smores around campfires. Hayley enjoyed swimming and liked the sand under her feet at beaches. Animals held a special place in her heart - her froggies, watching her birdies in the backyard, and her two special dog friends, Lady and Luna. The only thing more important than them was her family.

Hayley is survived by her parents, Kevin and Laurie; siblings: Alex (Bailey) Miller, Brent Plate, and Madison Plate; grandparents: Deb Mueller (special friend, Eldred), and Ervin Plate; aunts and uncles: Tim & Kim Mueller, Keith & Kristi Mueller, Jake & Nicole Balthazor, Curt & Becky Plate, Dean & Tia Plate, and Alan & Holly Plate; nieces and nephews: Cameron Miller, Braeden Miller, and Adrianna Miller; great-grandparents: Janet & Nic Steinmetz; and many cousins, especially Mackenzie and Mikayla Mueller.

Hayley was preceded in death by her grandparents, Larry Mueller and MaryAnn Plate.

## XI. DUP 15q ALLIANCE CORPORATE OFFICERS & BOARD MEMBERS

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Donna Bennett	Co-Founder and Board Member
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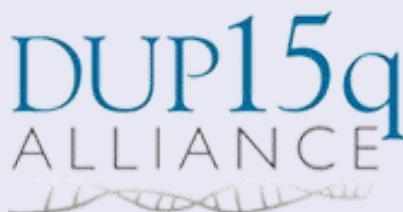
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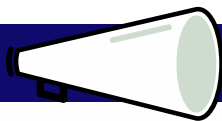
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<http://www.dup15q.org>



## XII. Upcoming Events



**9/8 Hope for Holden Event**  
**Springfield ,NJ**

**9/20 - Dup15q Believe Walk**  
**Denver, Colorado**

**10/7 - Dup15q Believe Walk**  
**Medford, New Jersey**  
**2nd annual international walk in France**

**10/6- 7th Annual GQ Event**  
**Merrionette Park, Illinios**

DUP15q  
ALLIANCE  
believe  
walk

*The Dup15q Alliance is a nonprofit 501(c)(3) organization that provides family support, and promotes awareness, research and targeted treatments for chromosome 15q11.2-13.1 duplication (dup15q) syndrome. (Dup15q) Dup15q Alliance offers help and hope for families affected by Dup15q Syndrome*

