

OCTOBER ■ 2010



# Down Syndrome Digest

## Celebrate Down Syndrome!!!

RRVDSS CELEBRATES DOWN SYNDROME AWARENESS MONTH WITH TWO INCREDIBLE EVENTS

*By Tiffany Phillips, Buddy Walk Chair*

October is Down syndrome awareness month and the Red River Valley Down Syndrome Society celebrates with two large awareness events, held over an hour apart in the Red River Valley region. DS Awareness month is about celebrating individuals with Down syndrome, their abilities and their contributions to our community.

The 7th Annual Buddy Walk is the first event of the month and will be held at the Love Civic Center Sports Pavilion in Paris, Texas on Saturday, October 16th. Walkers will enjoy a stroll down the Trail de Paris after a variety of activities for all ages (including, carnival games, bounce houses, concessions, and entertainment provided by Rocking J Music). It has even been rumored that local school administrators and political figures have volunteered to take their turn in a dunking booth. Participants can try their luck in the basket raffle, which will include great items from which to choose, and also enjoy hot dog or a slice of pizza as well. Festivities and registration will begin at 2pm with the one-mile walk beginning around 3pm.

Team registration is going on now and donations to be counted toward the team competition will run through Friday, October 15<sup>th</sup> until 7pm. Anyone is welcome to form a team or join an existing team. Participation is free, however, donations are appreciated. While the early-bird deadline for t-shirts and caps has passed, participants can still order these items to be received after the Red River Valley Buddy Walk. Teams are also competing for most team spirit and most walkers present awards to be given the day of the event.

On October 30th, hundreds will gather at Bobby Ferguson Park in Texarkana, Arkansas, for the Step Up for Down Syndrome Walk, benefiting the Texarkana chapter of RRVDSS. Located near the Four States Fairgrounds, the park features a scenic walking trail outlining a pond.

### *What's Inside:*

**ROSA'S LAW PASSES CONGRESS**

**MEET THE BOARD-FEATUREING TIFFANY PHILLIPS, VICE-PRESIDENT**

**PREVENTING HARMFUL RESTRAINT AND SECLUSION IN PUBLIC SCHOOLS**



*(Continued on page 7)*

*Meet The Board: Q & A with Vice-President, Tiffany Phillips*



*I wish people knew how dedicated the board members are in supporting individuals with Down syndrome. Most of us live and breathe the mission of our organization.*

**What is the funniest thing that ever happened to you?**

*When I was a kid, I got my finger stuck in an electric pencil sharpener. All the doctors and nurses though it was hilarious and laughed as they cut the sharpener off of my finger in the ER. Luckily, I wasn't seriously injured, I just hurt my pride.*

**What is something that people would be surprised to know about you?**

*I always said that I would never be a teacher because I saw how hard my mom worked, and here I am today.*

**What is your favorite quote?**

*"Therefore, do not worry about tomorrow, for tomorrow will worry about itself. Each day has enough trouble of its own"-Matthew 6:33-34*

**Tell us your favorites:**

**Book-***Scaredy Mouse* by Alan MacDonald and Tim Warnes (my kids love this book!!)

**Actor/Actress-***Julia Roberts*

**TV Show-***American Idol*

**Movie-***Steele Magnolias*

**Musical Artist-***Brad Paisley*

**Song-***Seven Bridges Road* by the Eagles

**Food-***Chinese*

**Hobby-***Camping*

**What is the best advice you have ever received?**

*Take one day at a time and celebrate even the smallest of milestones.*

**What is one thing you wish that more people knew?**

*REACH Center Taking Applications for Fall Semester Enrollment*

Applications are now being taken for the Fall Semester at the REACH Center. The semester has already begun and a few students are already attending classes.

"Right now, due to our teachers schedules' we are scheduling afterschool programs and classes," said REACH Center Education Director, Regina Rhodes.

With grant funding that has been received for the

REACH center and its' programs, members are offered one 45 minute session per week free of charge.

Additional sessions are available for a small fee of \$30 per session. While tutoring and instruction is offered specifically for reading and math, this program is unique in the fact that it can also be set up to help each student with their own personal

goals and plans , such as IEP goals. The program is also available to individuals with any cognitive disability.

"While children with Down syndrome are our first priority, this program is set up to help any child or adult with any type of intellectual disability," said Rhodes.

For more information on how to enroll for

the fall semester please contact the REACH center at 903-783-1922 or email Education Director Regina Rhodes at [rrhodes.rrvdss@gmail.com](mailto:rrhodes.rrvdss@gmail.com).



# Rosa's Law Passes Congress

Acting unanimously, the House of Representatives approved a bill to remove the terms “mentally retarded” and “mental retardation” from federal education, health and labor laws. The measure, called “Rosas’ Law” in honor of a Maryland girl who has Down syndrome, has already passed the Senate and is expected to be signed into law by President Obama.

“This law is about families fighting for the respect and dignity of their loved ones,” said Sen. Barbara Mikulski (D-Md.), one of the measure’s sponsors. “This change will have a positive effect on more than 6 million Americans.” She said the law will make the language of federal law consistent with that used by the Centers for Disease Control and the United Nations, and will not affect any services, rights, responsibilities or educational opportunities for people with intellectual disabilities.

Rosa’s law substitutes the terms “intellectual disability” and “individual with an intellectual disability” for the earlier terms, now considered outdated and stigmatizing by many self-advocates and their families. It does not cover entitlement programs, which include SSI, Medicare, Medicaid and Social Security.

“The bill is simple in nature but profound in what it will do when it is enacted,” Senator Mike Enzi (R-WY) said. “For far too long we have used hurtful words like ‘mental retardation’ or ‘MR’ in our federal statutes to refer to those living with intellectual disabilities. While the way people feel is important, the way people are treated is equally important. Rosa’s Law will make a greatly-needed change that should have been made well before today – and it will encourage us to treat people the way they would like to be treated.”

The inspiration for the law came from the actions of a family in Edgewater, Maryland. Last year, a mother of four named Nina

Marcellino found out her youngest daughter, Rosa, a child with Down syndrome, had been labeled retarded at school. Nina didn’t allow the R-word in her house, and none of her children described their sister that way. Nina teamed up with other parents and her state delegate to introduce a bill to change the terminology in Maryland state law. Before the bill was brought up for consideration in the Maryland General Assembly, they held a hearing on the implications of changing the term.

There were several witnesses at that hearing, but the testimony that had the greatest impact was given by an 11-year-old boy: Rosa’s brother, Nick. “What you call people is how you treat them,” Nick said. “What you call my sister is how you will treat her. If you believe she’s ‘retarded,’ it invites taunting, stigma. It invites bullying and it also invites the slammed doors of being treated with respect and dignity.”

The Marcellinos story is a perfect example of effective citizen advocacy,” Senator Mikulski said. “They pulled together to pull us all to another way of thinking. They fought for the respect and dignity of a loved one. The more than 6 million people with intellectual disabilities in America deserve that same respect and dignity.”

Peter V. Berns, CEO of The ARC of the United States, hailed the measure’s passage as “another historic milestone in our movement.”

“We understand that language plays a crucial role in how people with intellectual disabilities are perceived and treated in society,” Berns said in a statement. “Changing how we talk about people with disabilities is a critical step in promoting and protecting their basic civil and human rights.”



**Red River Valley  
Buddy Walk®**

**Saturday, Oct. 16th at 2 pm**

**Trail de Paris @ Love Civic Center  
redriverdss.org**

## NEWS YOU CAN USE

### New YouTube Channel for Siblings

Brian Skotko and Sue Levine, co-authors of *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*, have created a new YouTube Channel exclusively for brothers and sisters who have siblings with Down syndrome. On this site, Skotko and Levine will be answering some of the toughest questions asked by brothers and sisters, which are featured in their new book. Check out the YouTube Channel at [www.youtube.com/user/downsyndromesibbook](http://www.youtube.com/user/downsyndromesibbook)

### Registration Open for 2010 National State of the Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities

Registration is open for the 2010 National State of the Art Conference on Postsecondary Education and Individuals with Intellectual Disabilities that will be held on October 28 and 29 at George Mason University's new conference center in Fairfax, Virginia. This conference is being cosponsored by the National Down Syndrome Society and the George Mason University's Helen A. Keller Institute for Human Disabilities. NDSS sponsorship is made possible through a generous contribution from the Steve Riggio family and the conference is dedicated to the memory of Melissa Riggio.

Co-sponsors include the Steve Riggio family, the Office of Postsecondary Education (OPE) and the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, the American Association of Colleges for Teacher Education (AACTE), the University of Minnesota's Institute on Community Integration, ThinkCollege, Association of University Centers on Disabilities (AUCD), the Lawrence B. Taishoff Center for Inclusive Higher Education at Syracuse University and the American Association on Intellectual and Developmental Disabilities (AAIDD).

The conference will provide an opportunity for colleges and universities, researchers, program staff, parents and self-advocates to learn about the current state of policies, research, and practice in the field. Expert panelists will share effective practices and current research during breakout sessions with an opportunity for group discussion.

For more information and to register please go to [www.sccsid.org](http://www.sccsid.org).

### Free Down Syndrome Pregnancy Book and Website Launching

Expectant parents have a new resource to help them as they await the birth of a baby with Down syndrome. The website [DownSyndromePregnancy.org](http://DownSyndromePregnancy.org) will launch today, featuring a free downloadable pregnancy book, *Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome* by Nancy McCrea Iannone and Stephanie Hall Meredith.

In recent years, the area of prenatal testing has become more sophisticated, and more accurate blood tests are on the horizon for next year. Expectant parents learning about a Down syndrome diagnosis spend four to six months waiting for the birth of their baby and wondering about the future. This book is a practical resource for women who are moving forward with a Down syndrome pregnancy.

Iannone and Meredith, both parents of children with Down syndrome, recognized that expectant mothers with a prenatal diagnosis face some unique challenges that were not being specifically addressed in current literature. The authors understand the sense of isolation and grief after receiving a diagnosis and the sense of empowerment and validation that comes from understanding the condition.

The pregnancy book has been reviewed by expectant mothers, prominent leaders in the Down syndrome community, and a distinguished team of medical professionals, including Dr. Brian Skotko, a Clinical Genetics Fellow at the Children's Hospital Boston, and Dr. Harish Sehdev, a perinatologist and Director of the Prenatal Diagnosis Unit at Pennsylvania Hospital. Other professionals on the review team included obstetrician Dr. Joann Richichi, cardiologist Dr. Kan Hor, genetic counselor Cam Brasington, and breastfeeding specialists Dr. Sarah Riddle and Dr. Sheela Geraghty.

"This publication goes beyond just being a very useful resource for couples; it also has a very human side that comes through openly and compassionately. This book points out many important thoughts that I express to my patients .... The more information that a couple has, the better prepared they are to make it comfortable and enjoyable for their family." — Dr. Harish Sehdev, perinatologist and Director of the Prenatal Diagnosis Unit at Pennsylvania Hospital.

The audience of the book is specifically expectant mothers who are continuing a pregnancy; the book is not appropriate for women who are still weighing options about their pregnancy.

# Preventing Harmful Restraint and Seclusion in Schools Act, S. 2860

One of the activities in which National Down Syndrome Congress Governmental Affairs arm has been actively involved is the development of and advocacy for passage of the Preventing Harmful Restraint and Seclusion in Schools Act, S. 2860. This bill passed the House of Representatives and has been introduced in the Senate. It has not passed the Senate and is not yet law.

The bill prohibits the use of restraint, seclusion and aversive behavioral interventions except when the student's behavior poses an imminent danger of physical injury to the student, school personnel, or others. It also bans the use of certain types of interventions even in the very limited circumstances in which restraint can be used.

The bill also states: The use of physical restraint or seclusion as a planned intervention shall not be written into a student's education plan, individual safety plan, behavioral plan, or individualized education program. Because of this provision, several national groups are opposing the law.

It is extremely important that parents recognize that this is an issue for parents of all children with disabilities. As the school year begins, it is also imperative that parents do not allow restraint and seclusion to be written into IEP's when urged to do so by school officials. As Pat Amos, a national expert on the use of seclusion, restraint and aversives and a founding member of the APRAIS coalition states:

"One thing I know from all the cases of restraint and seclusion I have seen: you can't say they are 'for emergency use only' AND put them in the IEP. IEPs only work if they are positive plans of action; if they fail so badly that a restraint emergency occurs, everyone needs to be clear that they went outside the plan, the plan failed, the plan must be fixed. But once restraint or seclusion is IN the plan, then each usage means we FOLLOWED the plan, the CHILD failed, and the CHILD must be fixed by our continued ADHERENCE to the restraint and seclusion PLAN. The only way to turn this around is not to make ongoing plan failure an acceptable part of the plan."

Below is a letter from a mom with a young son with Down syndrome. It sadly reflects a situation which is all too common in our educational system.

Hi,

*I got your information from another Mom at NADS. My son is 8 years old and has Down syndrome. We live in Bridgeville, Illinois, a southwest suburb of Chicago. My son is very high functioning and has been reading since kindergarten. I have been pushed all over with him from school to school. I have fought for him to be*

*mainstreamed but the Special Ed director does NOT believe in mainstreaming.*

*When my son was in preschool he came home one day with an adult hand print welted onto his face. They claim it did not happen at school. I called the police department and they told me to take pictures. I talked to the school and the pediatrician. I showed them the pictures the next day and nothing was done.*

*XXXXXXX has been hurt several times by other children in special education rooms and now he is modeling the behavior he is being shown. When he was mainstreamed, he did great but he would get frustrated and would lie on the floor when he saw he was not doing the same worksheets as the other children. From day one the special education teacher gave me the feeling she had no love or compassion for special education children and I was correct.*

*XXXXXXX's IEP said would only be restrained if he was a threat to himself or other children. As the year went on XXXXXXX would be upset if I just touched his arm and he would scream. I knew this was not like him. His aide and special education teacher were constantly restraining him for not doing his work. I didn't realize how bad it was in the classroom and was bringing him from Dr. to Dr. and they told me finally go to the school. I would find my answer there.*

*I went one day to see him doing excellently in the regular classroom and was so proud. As soon as he walked into the special education room I saw his whole attitude change. The children were reading and sitting on the floor and he wanted to do what they were but the aide wanted him to do a worksheet instead. Since he did not listen both the aide and teacher grabbed him by both arms and pulled him back to his desk. He kicked his chair (I understood why) and they both immediately held both of his arms down. He turned and blew (not spit) in their faces to force them to let go of him and his aide who is a germ phobic freak (who once made him clean the toilet before he used it) got a glove and covered over his mouth and nose. This was not the first time either. It's documented on a piece of paper that recess and LUNCH are earned behaviors.*

*I would walk in at the end of the day with the teacher sitting on the floor having XXXXXXX in a bear hug with both of her heavy legs on top of his legs. Their documentation says tag team restraining is taking place. After two people would restrain him another two aides would take over.*

*I went to the superintendent who told me if I don't want him restrained find another school that doesn't do it. I went to DCFS*

*(Continued on page 7)*

SAVE THE DATE:

BUDDY WALK\*\*\*OCTOBER 16, 2010  
STEP UP WALK \*\*\*OCTOBER 30, 2010

# *New Technology Aims to Bring Peace of Mind to Parents*

EmFinders is teaming up with non-profit Project Lifesaver to extend the use of EmSeeQ, a cellular based recovery system that connects directly to the E-9-1-1 emergency location system, to help more families in need of locating their loved ones who may wander. Our joint mission is to bring peace of mind for families caring for loved ones with cognitive conditions, such as those individuals with Alzheimer's, autism, Down syndrome, and traumatic brain injury.

It is estimated that 10 million Americans are cognitively impaired by Alzheimer's, dementia autism, brain trauma or other circumstances. With respect to Alzheimer's alone, there are about 127,000 critical cases per year of affected individuals wandering off un-



expectedly -- and adding numbers from other types of cognitive impairments raises that number dramatically. With the EmSeeQ's national coverage, simplified procedures and reliance on the existing E-9-1-1 emergency location system, Project Lifesaver will be able to equip more law enforcement offices, public safety organizations and community groups with enhanced tools to proactively locate people at risk of wandering with cognitive disorders.

Based in Virginia, Project Lifesaver provides technology, resources and training to more than 1,150 participating public safety agencies across the U.S., Canada and Australia. Over the last 10 years, Project Lifesaver has performed more than 2,180 searches with no serious injuries or fatalities ever reported. By adding the EmSeeQ service, Project Lifesaver will offer an even more effective, efficient and state of the art technology to law enforcement agencies.

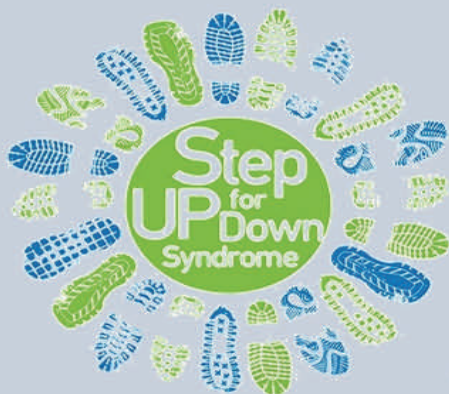
Because it relies on the existing E-9-1-1 emergency system, Project Lifesaver can now offer a solution that works at any time wherever it is needed, and requires no investment in additional equipment. At no incremental cost to law enforcement, the EmSeeQ provides all the tools necessary to find a wandering loved one.

To provide caregivers and family members with peace of mind and prevent a tragedy, the EmSeeQ emergency recovery system by EmFinders makes finding and recovering a lost loved one quick, safe and reliable. The wristwatch-style device uses cellular technology to enable the national E-9-1-1 emergency system to securely locate the wearer in the event of a wandering emergency. The device is effective and reliable nationwide and is the only device of its kind that integrates directly with the E-9-1-1 emergency response system.

"The EmSeeQ is a vital part of ensuring that organizations and public safety agencies continue to find individuals who wander as quickly as possible," said Gene Saunders, Chief Executive Officer of Project Lifesaver International. "Every minute lost in a search increases the risk of a tragic outcome. EmFinders has utilized their expertise to develop and build their products to effectively locate people at risk and bring loved ones home safely."

"Until there is a cure for cognitive disorders like autism and Alzheimer's, Project Lifesaver is here to help those affected and their loved ones," said Jim Nalley, founder and CEO of EmFinders. "The group's record of success is fantastic, and we are delighted to be teaming with an organization that has been at the forefront of helping individuals with cognitive conditions."

For more information about how EmSeeQ works, visit <http://www.emfinders.com/our-solution>. For more information about Project Lifesaver International, visit <http://projectlifesaver.org/>.



**Saturday, October 30th  
10 am**

**Bobby Ferguson Park  
@ Four States Fairgrounds  
Texarkana, AR**

**benefiting  
Red River Valley Down  
Syndrome Society - Texarkana  
Chapter**



## *DS Month Celebrations, cont.*

*(Continued from page 1)*

Once again, the event will feature carnival games, face-painting, a clown and several children's costumed characters. A live DJ will entertain as attendees gather at 10 am to register for the event and begin enjoying the festivities with their family and friends.

Unlike the Texas walk, there is still time to pre-order shirts for this event. All registrations of \$20 or more receive a free Step Up shirt. Those donations received by Saturday, October 9th will get their shirt on or before the day of the walk. Those wishing to get their last-minute donations in before the deadline can do so online at [redriverdss.org](http://redriverdss.org) or by attending the Shirt Deadline Party on October 9th from 6-7 pm at Starbucks, 2507 Richmond Road in Texarkana.

The Four States Step Up Walk has added something new this year to help teams. Priscilla Burnett, Step Up Committee Chair, explains that they have set up

time slots for Step Up team pictures hoping to eliminate any confusion or waiting. Team captains will be given the picture schedule ahead of time in order to help them gather their team in order to capture that moment in time.

Down syndrome awareness month is all about celebrating our loved ones and friends with Down syndrome. The Red River Valley Down Syndrome Society's mission is to improve and enrich the lives of those with DS through support, education and awareness. There's no better way to increase awareness of Down syndrome and the abilities of those with the extra 21st chromosome than to bring people together in a fun environment to share in our passion.

To find out more about the Paris or Texarkana walk, go to [www.redriverdss.org](http://www.redriverdss.org) and click on one of the walk logo's. Registration is easy and can be done online at the website as well.

## *Preventing Harmful Restraint and Seclusion, cont.*

*(Continued from page 5)*

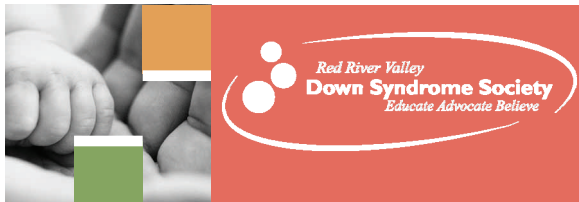
*and they told me another family also came forward against the same teacher and backed down when they heard the school would get a lawyer. I went to the police department and they said schools have immunity and can restrain children. Now to get rid of my son because of me (and I won't back down) they will not mainstream him anymore or put him in any of their schools. They want him in a program called AERO which he was in for the last two months of school since they did not give me a choice. All he did for the two months was color a rainbow! They didn't want him frustrated so they did not give him a pencil to write. He was in a classroom of children who could not speak and would scream all day. They had recess time and went on a lot of field trips. NO ACADEMICS! They are telling me I have no choice and this is the only option! HELP! Please let other parents know what is happening to our children. I will not back down I know my child knows how to write his first and last name, can add and subtract, spell, etc.,*

*and I will not let him regress. He needs an education and this school district needs to be held accountable.*

*Thank You,*

*Donna*

**To read the text of the bill introduced in the Senate, go to: <http://thomas.loc.gov> and key in S. 286 under bill number. To read an NDSC Action Alert about this bill, go to <http://capwiz.com/ndscenter/issues/alert/?alertid=14660126>. To listen to a podcast on this important issue, go to: <http://advocacyinstitute.org/expertsontherecord/RestraintSeclusion.CongressResponds.mp3>. If you would like a "no restraint" letter to send to your child's school district, contact [susan@ndscenter.org](mailto:susan@ndscenter.org).**



Non-profit  
Postage & Fees Paid  
Permit No. 188  
Paris, TX

6325 LAMAR ROAD, RENO, TX 75462

*Return Service Requested*

Disclaimer: The Red River Valley Down Syndrome Society (RRVDSS) assumes no specific or implied liability with respect to the interpretation, use, misuse or subsequent communication of editorial content or information contained in this publication. The opinions, beliefs and viewpoints are those of the individual authors and contributors and do not necessarily reflect those of RRVDSS, its directors, members or the editor of this publication. The content of Down Syndrome Digest is provided as a public service for informational purposes only and is not a substitute for medical or professional advice. RRVDSS does not endorse any particular therapy, institution or professional system. The information herein is presented as is, without warranty of any kind, express or implied.

## PRE-ORDER YOUR COOKBOOKS NOW

The RRVDSS cookbook will be out soon—containing 400 scrumptious recipes submitted by our members, families and friends. The price of the cookbook is only \$12 and pre-orders are being taken now. RRVDSS asks all of our members and friends to help us sell the cookbook. Pre-orders can be sent to the REACH Center at PO Box 6455, Paris, TX 75461-6455. Checks should be made out to RRVDSS for \$12 + \$3 each. shipping and handling if you want the cookbook(s) mailed to you. Online ordering is also available! The cookbooks should be in by early November, so they'll make super Christmas gifts!

### *Next Issue:*

CELEBRATE THE  
HOLIDAYS WITH  
RRVDSS!

MEET THE BOARD  
FEATURE

UPDATE ON ANNUAL  
AWARENESS  
CALENDARS

PLEASE CONTACT  
RRVDSS AT **903.783.1922**  
OR VISIT **WWW.REDRIVERDSS.ORG**  
FOR MORE INFORMATION.