The Down Syndrome Foundation
1st Annual Medical Conference

We are incredibly excited to bring to Roswell a medical conference for our doctors, nurses, caregivers, and families. This conference is meant to bring awareness for our medical professionals so that they can have a better understanding of how to treat and refer patients with Down syndrome. We will bring in doctors from out of state that work directly with individuals with Down syndrome to speak, provide knowledge, and networking opportunities. In Roswell, we know that most of our families have to travel out of the city or sometimes out of the state to seek medical attention. Bringing this conference will help in providing resources and awareness to our community.

One of our keynote speakers is Down syndrome behavioral expert Dennis McGuire, Ph.D., who helped establish a world-class medical care and research center for adults with Down syndrome under the umbrella of the Linda Crnic Institute for Down Syndrome. McGuire has more than 30 years of experience in the fields of mental health and developmental disabilities and is the former Director of Psychosocial Services for the Adult Down Syndrome Center of Lutheran General Hospital in suburban Chicago, the largest, most prestigious clinic for adults with Down syndrome in the United States. He helped establish the center, which serves over 4,000 unique adult patients with Down syndrome each year. We are very privileged that he will be assisting us in making this happen.

The date for this event is Saturday, June 3rd from 8am-4pm at the Roswell Convention Center. The day will consist of breakout sessions, keynote speaker, lunch, and we are working on having a meet and greet the night before for our medical professionals to network with Down syndrome specialist.

You can help us get the word out by talking to your medical professionals and letting them know what a great opportunity this will be for them to network, meet families, and gain knowledge and resources to help our community. If you are interested in volunteering for this event, we would love to have you! Call the office at 575-622-1099 or email us at info@dsfsenm.org for more information on how you can help.
Upcoming Events

**March 18**
“Beauty and the Beast” movie outing

**March 21**
World Down syndrome Day!

**April 4-5**
Buddy Walk® on Washington

**April 20-21**
Parents Reaching Out Conference

**June 3**
DSF Medical Conference

**June 26-30**
First Tee Golf camp

**July 3-14**
Swim Camp

**July 21**
DSF 5th Annual Educational workshop

**July 20-23**
NDSC Convention

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**“Beauty and the Beast” Movie outing**

Join us Saturday morning to watch the classic “Beauty and the Beast” at Allen Theaters Galaxy 8 on Saturday March 18th. Doors open at 9am, movie starts at 9:30am. Please be at the theater before 9:20am. The DSF will pay for each individual with Down syndrome, family members, and will have to pay $6.50 which includes movie ticket, small popcorn, and small drink. Please call the office at 575-622-1099 by March 10th to RSVP so that we can have an accurate head count for seating purposes. Hope to see everyone there!

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**Buddy Walk® on Washington**

The NDSS Buddy Walk® on Washington is an annual two-day advocacy conference that brings the Down syndrome community together to advocate for legislative priorities that impact the lives of people with Down syndrome and their families. Registration is now open for the 2017 Buddy Walk® on Washington. The registration deadline is March 27, 2017. Visit ndss.org for more information on registration fees, hotel and itinerary of events.

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**Parents Reaching Out 13th Annual Family Leadership Conference**

This conference will help families improve their skills in advocating for their children and in impacting the systems that affect their children. There will be fun networking opportunities with over 300 participants from around the state and a selection of workshop strands that will provide important information and perspectives to both families and professionals. Visit parentsreachingout.org for more information.

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**What we’ve been up to**

**Game Night re-cap**

**Cooking class re-cap**
How to prepare for Your Child’s IEP

DEVELOPED COLLABORATIVELY BETWEEN parents, teachers, and school district administrators, individualized education programs (IEPs) set social and academic goals for children and list any services a school district must provide for children to meet those goals.

The process of creating an IEP can feel overwhelming to parents, but good preparation for an IEP meeting (when IEPs are discussed and finalized) can help make the process less taxing and lead to greater success for students.

PREPPED AND READY?

Michael Remus is Director of Student Support Services at Cottonwood-Oak Creek School District in Arizona. As a former teacher with two sons who are differently-abled, he remembers the deer-in-the-headlights feeling from his first IEP meetings and encourages parents to do all they can to be informed at the beginning of the process. “Don’t come in to the meeting cold,” he said. “Call the school district beforehand and ask for procedural safeguards, an IEP meeting agenda, any forms you might be asked to fill out, and a draft of your child’s IEP at least a week prior to the IEP meeting.” Under the Individuals With Disabilities Education Act (IDEA), school districts are required to provide the drafted IEP, as well as a Procedural Safeguards Notice — a document explaining a parent’s and child’s rights regarding topics such as evaluations and how complaints must be handled and resolved. You may not automatically receive these unless you ask for them. Considering that members of your child’s IEP team will have already thoroughly reviewed the IEP, it’s important that you take time to read through it carefully, as well. Review the school’s assessment of and goals for your child, and identify any questions or concerns that need to be addressed during the IEP meeting. (Need suggestions? See “Question Everything” left).

DURING YOUR MEETING

Adequate preparation beforehand can make IEP meetings feel less intimidating. If one parent is unable to attend, many districts allow relatives or friends who know your child well to come in the parent’s place. That person may think of new questions to ask or help inform the IEP team about your child’s skills and personality — and put you at ease.

When you arrive to the meeting, have your list of questions and other materials you’ve been provided with you, so all relevant details are covered. Remus recommends bringing a notebook with prior IEPs, pictures of your child, medical issues, and lists of medications, which can help answer any questions the educators might have. If any questions do come up during the meeting that you don’t have time to discuss, make sure you get contact information for people who can best answer them.

QUESTION EVERYTHING!
As you prepare for your child’s IEP meeting, consider asking the following questions:
• What does ______ mean? Read through any materials the school has provided and ask for definitions of terms and/or policies you don’t understand.
• Who will attend the meeting?
• What will happen daily in the classroom to help my child progress toward his or her goals?
• How will the IEP goals be measured?
• What will happen if my child has behavioral issues?

DEFINING GOALS

This is a crucial step in the preparation for any IEP meeting. Although the school may have already set goals for your child in its draft IEP, you may not agree with them or want goals more targeted to your child’s needs or interests. “Parents can, and should, come up with their own goals for their child,” said Alissa Beck, B.Ed., M.A., SPED, Education Specialist at the Anna and John J. Sie Center for Down Syndrome at Children’s Hospital Colorado. “Goals don’t need to be complicated or numerous — just consider, what would I like my child to be able to do by the end of this year?” Goals also don’t necessarily need to be academic. They can be behavioral, social, or, if your child is a teenager, related to post-high school education or employment. Regardless, goals should apply to your child’s areas of need, be achievable in a single school year, and be specific and measurable. A goal like “reading,” for example, should be focused on what needs improvement, such as comprehension or phonetics. “If we don’t pinpoint specific skills, it’s difficult to assess progress and what needs improvement,” Remus said.

THROUGHOUT THE YEAR

Under IDEA, IEP meetings are required to occur at least once a year, but parents have the right to request more frequent meetings to review a child’s IEP as he or she surpasses, or has trouble meeting, goals. “I love it when we have teams who want to meet in six months because of growth,” Beck said. “But at the same time, if something isn’t working, we don’t want to wait six months to a year to fix it.” The law also requires regular progress reports for students who are differently-abled, just as typical students receive report cards. Both Beck and Remus agree that in between those updates, open communication with your child’s teachers is critical. Informal check-in emails can be very useful, whereas a communication notebook allows parents and teachers to answer questions and share what a child learned or struggled with on a particular day. “You are the expert on your child and the most critical part of the IEP team,” Beck said. “Everyone at the table should have your child’s best interests at heart. If you’re not feeling that you’re being understood or heard, it’s OK to reach out to your child’s principal, the special education director, or even local support groups to find someone to advocate for.”

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The Down Syndrome Foundation of Southeastern New Mexico is a 501(c)3, not for profit organization. It was started by a grassroots parent group in 2007. Its goals are to encourage and advocate on behalf of individuals with Down syndrome and their families. It does this by providing support for families, educators, and medical professionals as they support those with Down syndrome in southeastern New Mexico. Find out how you can help, call 575-622-1099 or visit our website at http://www.dsfsenm.org/

Christine Leon

Christine is 33 years old and loves shopping, cooking, baking, car shows, and cook outs. She is the only girl amongst 3 brothers. In 2016 Christine was chosen for the “Shining Star” program with the Department of Health that allowed her to make a collage board about herself that traveled New Mexico in and out of museums. Christine loves animals and has a passion for rescuing them. At church, Christine is involved in sign language singing and loves it. She volunteers for the Joy center and in the library at the Salvation Army. From hip hop to belly dancing, Christine does it all. After all this, spending time with family is most important.

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