October is Down Syndrome Awareness Month!

The Down Syndrome Guild of Greater Kansas City is celebrating Down Syndrome Awareness Month by disseminating information packets to local medical professionals. Please contact our office for additional materials!

Refer your patients to the very best resource....

DSG provides the following programs and services FREE OF CHARGE!
- Non-directive prenatal diagnosis support
- Post-natal diagnosis support
- Parent to parent match
- New parent welcome basket
- Quarterly support breakfasts
- Hospital meal voucher checks
- FREE counseling sessions with an LCSW
- Medical professional training

5960 Dearborn Street
Suite 100
Mission, KS 66202
913-384-4848
info@kcdsg.org
www.kcdsg.org
Three types of Down syndrome:

- **95%**: Trisomy 21
- **4-5%**: Translocation Down syndrome
- **~1%**: Mosaic Down syndrome

**Prevalence**

- Occurs in 1 in every 830 babies born in the United States.
- Approximately 6,000 births each year in the United States.
- About 250,000 people in the United States live with Down syndrome.

**Health risks for people with Down syndrome**

- Congenital heart conditions
- Gastrointestinal problems, such as obstructions
- Celiac disease
- Problems with memory, concentration, and judgment
- Hearing conditions, such as sensorineural hearing loss
- Eye problems, such as cataracts or far-sightedness
- Thyroid conditions

**Cognitive characteristics for some children with Down syndrome**

- Mild to moderate intellectual disability
- Difficulty navigating social situations
- Short attention span
- Impulsivity
- Stubbornness, a desire for routine & order
- Angry outbursts
- Self talk (talking out loud to him/herself) as a way of understanding and processing information

**Life expectancy for people with Down syndrome**

- ~60 years
- Up 456% between 1960 and 2007

**Support systems that help people with Down syndrome live fulfilling lives**

- Quality educational programs that augment natural learning
- High-quality, specialized health care, like Down syndrome clinics
- Stimulating and supportive home environment
- Positive family members and friends
Risk factors

- Advanced maternal age is the only known risk factor.
- Chance increases every year, especially after the mother is 35 years of age.
- Because younger women are more likely to have babies than older women, about 80% of babies with Down syndrome are born to women younger than 35 years of age.

80% Under 35

Prenatal testing for Down syndrome

Old recommendation
All pregnant women over the age of 35 be offered an amniocentesis.

New Recommendation
All forms of testing should be available to all women regardless of age.

Education is NEEDED about prenatal testing

45% of ACOG fellows and junior fellows rated their residency training regarding prenatal testing for fetal aneuploidy as "barely adequate or nonexistent".

28% Only 28% of ACOG fellows felt "well qualified" in general prenatal genetic counseling.

Prenatal Diagnoses of Down Syndrome: Delivering Results in Our New Age of Genetic Testing

Free, one-hour webinar that provides guidance for providers, physicians, nurses, and other healthcare professionals on communicating with expectant parents about a prenatal diagnosis of Down syndrome.

Watch the Webinar at www.mghacademy.org/downsyndrome

Other important Down syndrome organizations

National Down Syndrome Society
www.ndss.org

National Down Syndrome Congress
www.ndsc.org

Down Syndrome International
www.dsi-int.org

Massachusetts Department of Public Health
www.mass.gov/dph/downsyndrome

Massachusetts Down Syndrome Congress
www.mdsc.org

Massachusetts General Hospital Academy

About Massachusetts General Hospital Academy

The Massachusetts General Hospital Academy is dedicated to providing world-class educational programs and courses that improve clinical practice and lead to better care for patients and their families.

Accreditation: Partners HealthCare System is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Accreditation Council for Continuing Medical Education

Sources/References
1. National Down Syndrome Society
2. Centers for Disease Control and Prevention
3. Centers for Disease Control and Prevention
4. Centers for Disease Control and Prevention
Our Mission

The Down Syndrome Diagnosis Network (DSDN) supports families with current information and real-life accounts of life with Down syndrome during the prenatal to early childhood phases. DSDN is committed to facilitating unbiased, family-centered discussion of Down syndrome within the medical community. We strive to cultivate a culture of acceptance and inclusion for people with Down syndrome at all stages of life.

“We were blessed in that our doctors supported our values and beliefs.”—Lauren, Mom to Eddie

Real answers from real parents.

DSDN
DOWN SYNDROME DIAGNOSIS NETWORK
Inform • Support • Connect

PO BOX 78 • ZIMMERMAN, MN 55398
PHONE: (865) 456-5085
dsdagnosisnetwork.org
Supporting New & Expectant Parents

Down Syndrome Diagnosis Network (DSDN) seeks to support families receiving a prenatal or birth diagnosis for their child by providing them with up-to-date information.

We aim to equip parents with tips, facts and real stories that will assist them in navigating through the diagnosis.

DSDN achieves this through our website and social media where parents can receive daily resources directing them to the information they need.

Providing Feedback & Resources

DSDN assists patients in giving feedback to medical providers regarding their prenatal or birth diagnosis conversation. Additionally, we can provide medical professionals with the following resources to assist them in handling future diagnosis conversations:

- How to Deliver a Prenatal Diagnosis of Down Syndrome A compilation of professional recommendations for delivering a birth diagnosis of Down syndrome.
- Delivering a Down Syndrome Diagnosis A summary of best practices for medical professionals delivering a prenatal diagnosis of Down syndrome.
- Understanding a Down Syndrome Diagnosis (Joseph P. Kennedy, Jr. Foundation Lettercase) A medically reviewed resource for expectant parents receiving a diagnosis.
- Resources from local/national Down syndrome associations, groups and networks.

Connecting Parents

DSDN believes that a strong support system can make a great impact in the lives of parents raising a child. We have a deep desire to connect and support parents receiving a new Down syndrome diagnosis.

DSDN facilitates this through:

- Developing small and large online groups
- Connecting families in local communities to each other and nearby resources
- Establishing relationships locally and around the world for those with like experiences
The Down Syndrome Guild of Greater Kansas City (DSG) is a nonprofit 501(c)3 organization whose mission is to provide support and resources to individuals with Down syndrome and their families. The Guild seeks to provide the entire community with information and education to broaden awareness and foster positive attitudes regarding people with Down syndrome.

DSG provides programs and services to improve the quality of life for individuals with Down syndrome and their families. DSG currently serves over 1200 families and partners with 40 school districts and 22 hospitals to provide current, accurate information regarding best practices on supporting individuals with Down syndrome.
Resources

**DSG Center**
DSG has a state of the art 8000 square foot center which houses our staff, lending library and First Down for Down Syndrome. The center is open Monday-Friday from 8am to 4pm. DSG regularly hosts seminars and trainings for families, educators and professionals at the center.

**Website**
The award winning DSG website, www.kcdsg.org, receives thousands of hits each month. Donations and orders can be placed directly through the website. The website is updated monthly to reflect new events, showcase photos from past events and share latest research information.

**Connections Newsletter**
Connections is published bi-monthly and disseminated to over 3000 recipients. Connections covers educational information, medical and research updates, current events, success stories, community group listings, fundraising information and other pertinent topics related to supporting individuals with Down syndrome.

**Just Like You Film**
Just Like You - Down Syndrome Film explores the life, hopes, challenges and dreams of three teenagers living with Down syndrome. The film's primary goal is to open hearts and change perspectives. The film is available in English, Spanish and Portuguese. Watch the film and download additional materials at www.justlikeyou-downsindrome.org

**Expectant Parent Support**
DSG's offers expectant parents accurate and positive information on Down Syndrome along with suggested reading materials support information and adoption resources. Prenatally diagnosed families are offered Parent to parent matches and provided a welcome basket. Families and medical professionals are encouraged to contact the DSG for more information.

**New Parent Magazine**
DSG's award winning New Beginnings Magazine is designed to educate and comfort new parents of a child with Down syndrome. The magazine is filled with accurate information, stories from families and lists of resources. New Beginnings is presented to parents as early as possible and at no cost. DSG works cooperatively with local hospitals and physicians to distribute New Beginnings to parents.

**Understanding a Down Syndrome Diagnosis Booklet**
DSG provides prenatally diagnosed families an accurate, balanced, and up-to-date booklet to help understand a Down syndrome diagnosis. The booklet is the only prenatal resource to have been reviewed by representatives of the national medical and Down syndrome organizations.

**Resource Library**
Books, videos and brochures about Down syndrome are available on loan at no cost. The Guild maintains approximately 300 titles readily available for families and professionals.

Education

**Annual Conference**
DSG is proud to host an annual educational conference which brings together experts in the field who discuss best practices in working with individuals with Down syndrome.

**Seminars and Workshops**
DSG host seminars and workshops throughout the year to provide ongoing support. Some of our most popular seminars include:
- **Mind Your Marriage**: Couples reconnect and are counseled on how to relieve stressors in their marriage
- **Seminar Series**: A training for educators, parents and service providers and other interested parties to learn how to successfully engage, instruct and enjoy your student with Down syndrome.

**Conference Scholarships**
DSG offers financial funding for families to attend other local and national conferences that will benefit their family.

**Inclusion Solutions**
DSG's award winning Inclusion Solutions E-Newsletter is chock full of tips, strategies and resources for supporting and providing inclusive opportunities for students with Down syndrome.

**Down Syndrome Specialists**
DSG partners with 45 school districts who have named Down Syndrome Specialists. They serve as liaisons between DSG, families and their individual districts. Specialists are given free registration to all DSG educational events, a resource manual and are hosted for breakfasts twice during a school year to discuss the districts needs in serving their students and how DSG can provide assistance to meet those needs.
Outreach

Parent to Parent Network
As soon as the Guild is informed of a new baby with Down syndrome, a parent from our network contacts the new parents to offer support, friendship and information on how to receive support from the Guild and other local resources.

Support Breakfasts
Quarterly new parent breakfasts are hosted at the DSG Center to welcome new and young families and provide them much needed support and resources. Toddler and Grandparent breakfasts were added in 2006 to broaden the range of supports DSG offers.

Birthday Club Program
Everyone loves to be remembered on their special day. DSG sends out a birthday greeting with a treat to each individual with Down syndrome in our database during their birthday month. It’s our special way of reminding them how much DSG loves them.

Meal Voucher Program
Some of our families will spend an extended amount of time in the hospital with their children due to medical complications. DSG will provide meal vouchers to offset expenses incurred while staying in the hospital. Families can also request a visit from another member of the Guild during their stay in the hospital.

Changing Lives Presentations
Parent led panel presentations educate physicians on best practices support when giving the diagnosis of Down syndrome. Presentations break down stereotypes, provided accurate information about quality of life for people with Down syndrome and ensure a positive experience for newly diagnosed families.

Community Groups
DSG provides administrative support and funding to 14 community groups who meet throughout the Greater Kansas City area. Groups provide social and educational opportunities.

Social

All Guild Social Events
DSG hosts several events each year for all members to come together and fellowship one another. Among these events are the Easter Eggstravaganza, Red Barn Farm outing, Carnival and Holiday Party. Families look forward to these events as an opportunity to network and share information and resources with one another.

Adult Group
Individuals with Down syndrome over the age of 18 meet for social activities such as dinners, bowling, movies, parties and dances.

Siblings Events
DSG hosts events each quarter for siblings that have a brother or sister with Down syndrome. Activities include opportunities to meet other siblings, explore feelings and questions about their sibling with Down syndrome and how their relationship may change in the future.

STARS
Special Teens Achieving Real Success provides social opportunities for teenagers with Down syndrome. STARS participants gather in a safe social environment while learning life, vocational and social skills which will help them succeed at home, school and in the community.

Step Up for Down Syndrome Walk
The Step up for Down Syndrome Walk is one of the largest in the nation with over 8,000 participants. The walk is the primary fundraiser for the DSG with proceeds providing funding for DSG programs and services. Please make a team to increase awareness and support our mission! Additional information is available at:

www.stepupfordowns Syndromekc.org
First Downs for Down Syndrome (FDFDS) teams up with the Kansas City Chiefs Offensive Line to raise money for the Down Syndrome Guild, the Down Syndrome Clinic at Children’s Mercy Hospital and other Down syndrome organizations.

A number of fundraising events are held each year to raise funds and provide greater awareness of Down Syndrome. Events are advertised in DSG’s Connections newsletter and open to any interested parties.

- Private Cellar Wine Tasting & Auction
- Huddle Time Sports Auction
- First Downs Golf Classic
- Dolls & Desserts for Down Syndrome
- Step Up for Down Syndrome Walk
- First Downs & Take Downs High School Fundraisers

Thank you to the Kansas City Chiefs for their strong support!

For information regarding events or other fundraisers please contact, Amy Stoll, Executive Director, at 913.689.2773 or via email stoll@dfds.org. You can also learn more by visiting our website at www.fdfds.org

Proudly serving Kansas City families and professionals since 1984!
Facts About Down Syndrome

Named after John Langdon Down, the first physician to identify the syndrome, Down syndrome is the most frequently occurring genetic condition. Down syndrome occurs in one in 691 births, and is present in all races and socio-economic groups. Down syndrome is a chromosomal disorder caused by an error in cell division that results in the presence of a third chromosome 21 or "Trisomy 21." This additional genetic material causes the identifying features as well as the cognitive and developmental delays which are common for individuals who have Down syndrome.
Myths and Truths

Myth: Down syndrome is a rare genetic disorder
Truth: Down syndrome is the most commonly occurring genetic condition. One in every 691 births is a child with Down Syndrome. Approximately 5,000 babies are born with Down syndrome each year and there are 250,000 people in the United States who have Down syndrome.

Myth: Down syndrome is hereditary and runs in families
Truth: Most cases of Down syndrome are sporadic, chance events. However, in the instance of translocation, one parent may be identified as a carrier of the translocated chromosome. Down syndrome does not otherwise run in families and a sibling or aunt does not have a greater chance of conceiving a child with Down syndrome.

Myth: There is little community support available to help parents raise a child with Down syndrome
Truth: There are over 300 Down syndrome support organizations in the United States which provide a variety of programs and services to individuals with Down syndrome and their families.

Myth: Most children with Down syndrome are born to older parents
Truth: Eighty percent of children born with Down syndrome are born to women younger than 35 due to higher fertility rates. However, research has shown a link between the incidence of having a child with Down syndrome and maternal age.

Myth: The life expectancy of people with Down syndrome is 30
Truth: Thanks to advances in medical and clinical treatment and opportunities to thrive, as many as 60% of adults with Down syndrome reach age 55, and many live longer.

Myth: People with Down syndrome have severe cognitive delays
Truth: Most people with Down syndrome have cognitive delays that are mild to moderate. IQ is not an adequate predictor of measure of the functional abilities of people with Down syndrome. People with Down syndrome have great potential if given

Myth: Adults with Down syndrome cannot form interpersonal relationships, or marry
Truth: People with Down syndrome are quite capable of forming long term loving relationships at all stages of their development. Many people with Down syndrome will date and some will get married and live with support from their families or programs.

Myth: Adults with Down syndrome may be unable to work or attend college
Truth: Business owners seek adults with Down syndrome for a variety of positions. They work in offices, banks, corporations, nursing homes, hotels and restaurants. People with Down syndrome bring to their jobs enthusiasm, reliability and unparalleled dedication. There are over 200 colleges currently offering post secondary opportunities for people with disabilities.

Myth: Parents who receive a pre-natal diagnosis of Down syndrome will often choose to terminate their pregnancies
Truth: While some parents choose to terminate a pregnancy upon receiving a diagnosis of Down syndrome, many keep their babies. Many parents also consider adoption as an option. There are 200 families registered who have indicated they would like to adopt a child with Down syndrome.

Myth: Students with Down syndrome are placed in and benefit from segregated special education programs
Truth: Children with Down syndrome are included in regular academic classrooms across the country. Students may be integrated into specific courses or fully included in the regular classroom for all subjects. The degree of inclusion is based on the ability of the individual, but the goal is full inclusion.

Myth: All people with Down syndrome will develop Alzheimer's disease
Truth: Approximately twenty-five percent of adults with Down syndrome over the age of 35 show clinical signs and symptoms of Alzheimer's-type dementia; the percentage increases with age. The incidence of Alzheimer's disease in the Down syndrome population is three to five times greater than in the general population, which is 5-10 percent in people over the age of 65.
Facts About Down Syndrome

- 1 in every 691 births will be a child with Down syndrome.
- There are 400,000 individuals with Down syndrome living in the United States.
- 5,000 babies are born with Down syndrome each year.
- The average lifespan of a person born with Down syndrome today is 55-60.
- 45% of individuals with Down syndrome will have a congenital heart condition.
- All people with Down syndrome will experience some level of cognitive delay.
- Individuals with Down syndrome benefit from early intervention services which include speech, occupational and physical therapy.

People First Language

The words we use have the power to help or hurt. It’s imperative that people who support individual with Down syndrome use People First Language at all times. People with Down syndrome have the same rights as everyone else and should be treated with respect. Remember to use People First Language in all your interactions to convey respect and to model by example.

Spelling

The correct spelling is Down syndrome. There is no apostrophe ‘s’ following Down. Dr. John Langdon Down provided the first formal description of the syndrome, but he did not have Down syndrome and therefore no possessive is used. Also, the ‘s’ in syndrome is not capitalized.

A Developmental Disability

Down syndrome is a chromosomal disorder that is present at conception. Using the term ‘birth defect’ or ‘disease’ in relation to Down syndrome is incorrect. There is no known cause or cure for Down syndrome so these terms are inaccurate.

People with Down syndrome usually experience mild to moderate physical and intellectual delays. When referring to a person with Down syndrome, the terms mental retardation and mongoloid are considered outdated, offensive and should be avoided.

Prenatal screening and diagnostic tests may detect Down syndrome in the womb. A karyotype test is typically done shortly after birth to provide parents a definitive diagnosis. Chromosome variations occur among people with Down syndrome. They are as follows:

Trisomy 21 Ninety-five percent of people with Down syndrome have an extra #21 chromosome in every cell of their body. This is known as Trisomy 21.

Translocation Three to four percent have an additional #21 chromosome attached to another chromosome. This is called translocation Down syndrome. In this case, a parent may be a carrier of a balanced translocation.

Mosaicism About one percent of people with Down syndrome have an extra #21 chromosome in some cells, but not in others. This is called mosaic Down syndrome.

Generalizations

Avoid generalizations about people with Down syndrome such as ‘they are always loving’, ‘always smiling’, or ‘perpetually happy’. People with Down syndrome are not all alike.

The abilities and characteristics among individuals with Down syndrome can be best described as the same for those in the general population.

Judgment

Please avoid judgmental terminology. A person with Down syndrome does not “suffer from”, and is not “a victim of” or “afflicted with” Down syndrome. Down syndrome is not a disease and these references only diminish a person’s dignity.

Alternate suggestions for describing the syndrome include “living with Down syndrome” or he/she has a medical condition known as Down syndrome.
Down Syndrome Guild of Greater Kansas City

- Formed in 1984 by a group of parents seeking to support one another
- Welcomes approximately 50 new babies with Down Syndrome each year
- Serves more than 1,100 families in the Greater Kansas City area
- Provides administrative and funding support to 15 community groups
- Partners with 22 local hospitals to provide information to new families
- Provides support and assistance to educators in 45 school districts
- Seeks to be the number one resource on Down syndrome in Kansas City
- Hosts one of the largest Down syndrome awareness walks in the nation
- Facilitates social and educational opportunities for throughout the year
- Offers community awareness presentations to breakdown stereotypes
- Envisions a world where all people with Down syndrome are valued