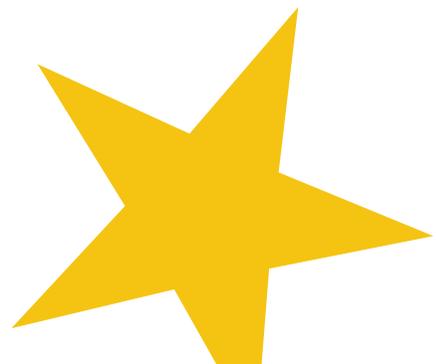


**For Expectant and
New Parents of
Children with
Down syndrome**





Dear New Family,

Congratulations on the birth of your baby and on your growing family! While there are many emotions you may be experiencing, you may also be wondering, "What does this mean and what do I need to do first?" Club 21 wants you to know we are here for you and ready to provide support to you and your family. Our motto is "Together is Better."

Club 21 helps families assemble the building blocks necessary at every step of development as they construct a fulfilling life for their child. These blocks are comprised of emotional support, information, education and connections. Our First Steps program is designed to assist new and expectant parents as they begin their journey of caring for their baby in each of these areas. Often parents are looking for support with issues related to all areas of development. We have guest professionals from Speech, Occupational and Physical Therapies who visit First Steps on a regular basis to provide an informal opportunity for you to ask your specific questions and glean from their knowledge.

We look forward to meeting you at Club 21. You will have a chance to show off your new baby, gather information and meet other parents and babies with Down syndrome.

Kind Regards,

A handwritten signature in black ink that reads "Nancy Litteken".

Nancy Litteken,
Executive Director





WHO WE ARE!

Club 21 envisions a society enriched by the inclusion of individuals with Down syndrome. Club 21's mission is to provide the educational tools and resources that enable individuals with Down syndrome to be fully included.

How do we do that?

We Support, Educate, Advocate and Celebrate!

Club 21's goal:

Independence, Access and Belonging!

Club 21's core values are:

Family Support: You are not alone!

Parent Involvement: We are family!

Innovation: Try something new!

Raising Expectations: We can do it!

Inclusion: We belong.



PARENTS FIRST CALL PROGRAM

For expectant and new parents of children with Down syndrome

WELCOME NEW PARENTS

Congratulations on your new baby! As parents who have experienced the birth of a baby with Down syndrome, we know that this is a time of mixed emotions. Receiving a prenatal diagnosis that your baby will have Down syndrome can come with unique challenges and new experiences. The most important thing to remember is that your baby is a baby first and not defined by his or her diagnosis of Down syndrome.



AND EXPECTANT PARENTS

Learning that your baby has Down syndrome is an overwhelming and emotional experience for most parents. You may initially feel confused, frightened, angry, saddened, and/or isolated. We offer you the opportunity to speak with experienced parents who can answer your questions and provide a realistic picture of raising a child with Down syndrome. We have information, resources and connections available that can help you make important decisions for your family.

“ I walked into Club 21 for the first time as an expectant mother who knew nothing about Down syndrome. I was so scared. After meeting with staff and other moms, I left with hope, knowledge and support. I was able to enjoy my pregnancy and joyfully welcome our new baby!”

– Kate, Club 21 parent

YOU ARE NOT ALONE

A dedicated group of experienced and trained parent mentors who have children with Down syndrome are available 24/7 to offer you support, listen, share, answer questions, and provide valuable information through Club 21's First Call Program.





“ I felt scared and alone when I found out my baby had Down syndrome. I had no idea what this diagnosis would mean for my baby and family. Club 21 was there to answer my questions and provide support, resources, community and hope.”

– Pam, Club 21 parent



PARENTS FIRST CALL PROGRAM OFFERS:

- Accurate information about Down syndrome for expectant and new families.
- The opportunity to talk with other parents about your concerns and questions.
- A chance to meet children with Down syndrome and their families.
- Support groups for parents, including a network specifically for fathers.
- Assistance locating early intervention services with local Regional Centers.
- Access to Club 21’s resources, programs and community events.

CONNECTING WITH PARENTS FIRST CALL

Club 21 makes First Call parent connections based on:

- Geographic area
- Similar health issues
- Ethnic background
- Religious background
- Primary language

REACH OUT

When you are ready, whether you are an expectant parent or a new parent, make Club 21 your first call:

www.clubtwentyone.org Phone (626) 844-1821





WHAT ARE THE PHYSICAL CHARACTERISTICS OF DOWN SYNDROME?

There are various common physical features among babies with Down syndrome. Not every baby born with Down syndrome will possess each of the characteristics. Many characteristics most commonly associated with Down syndrome can also be found in the general population. Some more noticeable common physical features found in babies with Down syndrome include:

- Low muscle tone (hypotonia) which makes muscles appear relaxed or “floppy”
- Loose joints
- Almond-shaped upward slanting eyes
- A flattened face and/or nose bridge
- Smaller ears, hands, and/or feet
- Small pinky fingers that sometimes curve toward the thumb
- A single crease across the palm of the hand (palmar crease)
- A deep groove between the first and second toes
- A short neck
- A protruding or larger tongue
- Tiny white spots on the colored part of the eye (Brushfield spots)



Can Down syndrome be treated or cured?

Down syndrome is a lifelong condition. Although it cannot be cured, medical professionals know more about it now than ever. Getting the best care early on can make a big difference for individuals with Down syndrome and improves the likelihood of a full and meaningful life.

It should be noted that there is no correlation between the number of characteristic features a baby has and the child's cognitive ability.



How will having Down syndrome affect my baby?

Babies born with Down syndrome will grow and develop like all other babies, but those with Down syndrome generally develop at a somewhat slower pace. Children with Down syndrome may be delayed in achieving milestones such as walking, talking, and eating compared to typically developing children. Children who have Down syndrome may also face intellectual and behavioral delays. Having a loving home environment and early intervention and special education services will positively influence a child's development in all areas.

What is the life expectancy of people with Down syndrome?

Over the years, medical research, technology, and practices have helped prolong individuals with Down syndrome's life span. Today the majority of individuals will live upwards of age 60 or 70.

Reprinted from ndscenter.org. For additional resources, please contact the National Down Syndrome Congress at (800) 232-6372 or info@ndscenter.org.



Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability-to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip-to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Colosseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland??" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever go away...because the loss of that dream is a very, very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.



DOWN SYNDROME FACT SHEET

- Down syndrome is a genetic condition that occurs when there is an extra copy of the 21st chromosome. The medical term is Trisomy 21. The additional genetic material causes delays in the way the body and the brain develop.
- Down syndrome is the most commonly occurring chromosomal condition. One in every 700 babies in the United States is born with Down syndrome.
- Down syndrome affects all races and economic levels.
- More than 400,000 people in the United States have Down syndrome and an estimated 3 million people worldwide.
- 80% of mothers having children with Down syndrome are under the age of 35.
- Children with Down syndrome are really more like other children than they are different.
- This generation of individuals with Down syndrome have the advantages of early intervention, access to public education and proper medical treatment. This has led to an increase in IQ and a longer life expectancy.
- Individuals with Down syndrome attend school, work, have meaningful relationships, vote and contribute to society in many wonderful ways.
- Children with Down syndrome often participate in regular classrooms, learn to read, and are fully integrated into community activities.
- A life with Down syndrome is a life well worth living and worth knowing!

PEOPLE FIRST LANGUAGE

- The correct name of the diagnosis is Down syndrome. There is no apostrophe (Down). The “s” in syndrome is not capitalized (syndrome).
- An individual with Down syndrome is an individual first and foremost. The emphasis should be on the person, not the disability. A person with Down syndrome has many other qualities and attributes that can be used to describe them.
- Encourage people to use people-first language. “The person with Down syndrome” not “the Down syndrome person.”
- Words can create barriers. Recognize that a child is “a child with Down syndrome.” Or that an adult is “an adult with Down syndrome.” Children with Down syndrome grow into adults with Down syndrome; they do not remain eternal children. Adults enjoy activities and companionship with other adults.
- It is important to use the correct terminology. A person “has” Down syndrome, rather than “suffers from,” “is a victim of,” “is diseased with” or “afflicted by.”
- Each person has his/her own unique strengths, capabilities and talents. Try not to use the clichés that are so common when describing an individual with Down syndrome. To assume all people have the same characteristics or abilities is demeaning. Also, it reinforces the stereotype that “all people with Down syndrome are the same.”



Words you'll hear and may not know:

Early Intervention

Services provided to infants and toddlers with disabilities ages birth to three and their families through a comprehensive program or individual providers. Down syndrome is a lifelong condition. Services early in life will often help babies and children with Down syndrome to improve their physical and intellectual abilities. Most of these services focus on helping children with Down syndrome develop to their full potential. These services include speech, occupational, and physical therapy, and they are typically offered through early intervention programs in each state. Children with Down syndrome may also need extra help or attention in school, although many children are included in regular classes.

IFSP/IEP

Individualized Family Service Plan (early intervention document) and Individual Education Program (public school document).

Speech Therapy

Works on language, listening, and feeding issues. Speech-language therapy can help children with Down syndrome improve their communication skills and use language more effectively. A speech-language therapist can help them develop the early skills necessary for communication, such as imitating sounds. The therapist also may help an infant breastfeed because breastfeeding can strengthen muscles that are used for speech.

Physical Therapy

Works on gross motor skills for large muscle groups, such as walking, sitting, and crawling. Physical therapy includes activities and exercises that help build motor skills, increase muscle strength, and improve posture and balance. Physical therapy is important, especially early in a child's life, because physical abilities lay the foundation for other skills.

Occupational Therapy

Works on fine motor skills, such as manipulating objects with hands as well as handwriting.

Hypotonia

Low muscle tone, common in people with Down syndrome.



Chromosomal abnormalities

It is an “abnormality” of the 21st chromosome that causes Down syndrome. All of the other chromosomes are normal. Even the 21st chromosome is normal; there’s just too much of it. Down syndrome is not caused by anything that the parents did before or during pregnancy.

Trisomy 21

Most people have 23 pairs of chromosomes. Trisomy 21 is by far the most common type of Down syndrome (95%) and means that instead of two 21st chromosomes, a baby was born with three 21st chromosomes, thus causing them to have Down syndrome.

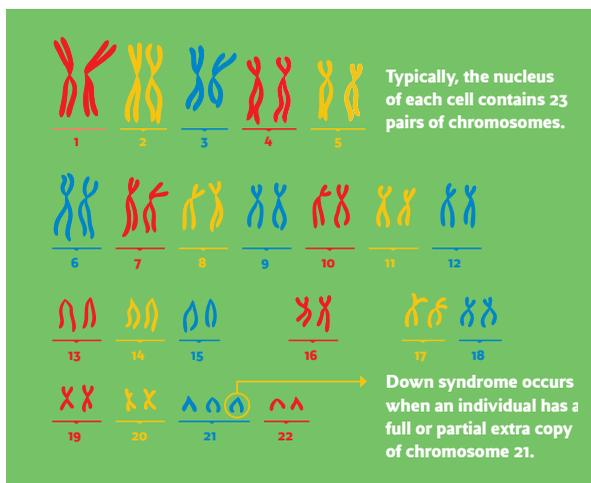
This chromosome division occurs immediately at conception, and the extra chromosome is found in all of the cells.

Mosaicism

This is the least common form of Down syndrome (1-2%). Chromosomes divide unevenly, but not until the second or third cell division after conception, meaning only some of the cells have the extra chromosome.

Translocation

In translocation, a part of the 21st chromosome has broken off and attached itself to another chromosome, providing extra genetic material in all of a person’s cells. Only 2-3% of babies with Down syndrome have translocation.



Club 21 Programs

First Steps - Come and enjoy good company as we celebrate our wonderful children together. This is a time of open play; there is no pressure. It is a time when you can let your little ones play while you chat with other moms and dads.

- Come and meet others on the same journey!
- Be encouraged.
- Make connections and new friends.
- Ask questions.
- Receive up-to-date resource information from visiting OTs and PTs and SLPs.
- Enjoy great toys and fun.
- Expectant parents can come and be supported in a safe place.

Age range: Babies 0 to 3

Stepping up - Club 21's program Stepping Up is a uniquely designed program that supports parents and children on their educational pathway. This 4 level program prepares families for transitions, navigating school systems and teaches the fundamental educational, social and life skills necessary for an independent life.

Age range: 18 months to 8 years

ECAR - Every Child A Reader is a one-on-one literacy tutoring program focusing on the development of reading and writing skills. Club 21 aspires to graduate an entire generation of capable readers with Down syndrome who will, as a result, be more independent and confident in their daily lives.

Age range: Kindergarten and up

Club F.U.N. - (Friends Understanding Nuances) - All the Club F.U.N. programs use Social Thinking Vocabulary (STV) and Concepts to enhance understanding and promote social competency growth. Year one, monthly 2 to 1 intensives with a speech and language pathologist followed by monthly social competencies classes in years two and three.

Age range: 8 to 12

CREW - (Creating Relationships and Equipping the Way) - The CREW program builds off of the Social Thinking Vocabulary (STV) and Concepts to enhance understanding and promote social competency growth. CREW provides interactive ways to foster friendships within the group and will teach skills that will be used within your home, school and communities.

Age range: Middle schoolers

Club Connections - Club Connections is a social competencies and life skills group that builds the foundational skills (relationships, independence, work) that will help each individual achieve their hopes and dreams.

Age range: High school +

Educational Partnership - A series of workshops created to support and train families and teachers so that children with Down syndrome can be included in school classrooms with their typical peers.

IEP Workshop (Individual Education Plans) - A workshop created to help families understand and navigate this important part of their child's education. IEP workshops will explain how an IEP works and provide parents with the resources to prepare for their child's IEP meeting.

Support Groups - Sibshops (sibling support group), Dads Appreciating Down Syndrome (D.A.D.S.), Moms Meet-up, Bienvenidos (Spanish speaking community group), and South Bay Community Group.

