



International 22q11.2 Foundation

Newsletter March 2026



Greetings from the International 22q11.2 Foundation!

As we welcome spring, we are looking forward to our annual [22q at the Zoo](#) event on May 17th (see p. 2). We also encourage you [apply to light up](#) your local buildings and monuments on November 22nd to make 22q differences visible (see below).



On pages 3 and 4, you can find our Medical Advisory Board's recommendations for vaccination. On p. 5, you will get to read the inspirational story of Dougie Bedinger III, who is aspiring to be a professional baseball player.

We provide information on how 22q11.2 deletions and duplications happen (p. 6), as well as research summaries on assisted reproductive technology (p. 7) and chronic inflammatory arthritis (p. 8).



Back in February, we posted links to our Heart Series and Brain and Nerves Series on social media (sample posts on the left). We are excited to let you know that the 7 info sheets of the Eye Series have now been published (p. 9). This is the 10th series in our [Hearts Conditions Explained](#) section! Also on page 9 of this newsletter, we include all the links to the current clinical recommendations documents. The two main documents from 2023 are available in English (original), Spanish, French, and Chinese.



We couldn't do our work without your support! Please consider making a [donation](#). Thank you very much. Happy reading!



2026 Lighting Request Letter Now Available

Let's raise awareness for 22q differences!

We invite you and your town to join an international movement of lighting up buildings and monuments in red on the evening of **November 22nd** (22/11; or 11/22 in North America) as a play on the name of the 22q11.2 deletion and duplication syndromes.

Some buildings may already have an online system for submitting lighting requests. If you do not find an online form, you can use a letter from our Foundation to **request red lighting on Sunday, November 22nd, 2026**. Click on image of the letter on the right to access the pdf file of the letter. **Download** the file to your own drive or cloud. Fill in the name of the building and the city or town, then email or mail the letter to the government or organization that manages the building.

On the night of **November 22nd, 2026**, take pictures of yourself with the illuminated building and share them on social media.

Together, we will light up the night for 22q differences!

Light up the Night for 22q11.2!

Greetings from the International 22q11.2 Foundation, Inc.
November is 22q11.2 Awareness Month!

22q11.2 deletion and duplication syndromes are under-recognized genetic conditions that affect about 1 in 1000 pregnancies and 1 in 2000 live births. These conditions occur when a very small piece of chromosome 22 is missing or extra, resulting in the loss or gain of about 50 genes that help direct how the body is formed and functions. The most common associated features include birth defects (such as heart, palate and kidney problems), multiple medical conditions (including low calcium, difficulty fighting infection, feeding and walking difficulties, and seizures), developmental delay, learning differences, and behavioral health problems, such as ADHD, anxiety, autism, and psychiatric illness. Many individuals require care from multiple specialists across the lifespan, but there is also very broad variability.

Most deletions and duplications are the same size with a subset being a bit smaller. All can occur randomly for the first time in the person who has the chromosome difference and nothing that the parents did or did not do cause it to occur. However, since a person has the deletion or duplication there is a 50% chance of passing it on in every pregnancy.

Chromosome 22q11.2 differences are the most common chromosomal conditions after Down Syndrome. However, most people have never heard of chromosome 22, and some people with these differences spend years searching for a diagnosis. To increase public awareness in 2016, La Asociación Síndrome 22q11 in Spain launched an awareness campaign entitled "Luces por el 22q" (Lighting the Night for 22q). Buildings and monuments were illuminated in red on **November 22, 2016** in many parts of the world but 11/22 in North America as a play on the name of the chromosome difference. Cities in Belgium, Poland, Canada, Finland, Germany, and the USA soon followed. At the bottom of this page are example photos from November 22 of previous years, where buildings were lit up in red to support 22q awareness. Please consider joining this international endeavor so that no child or adult struggles to find a diagnosis in a timely fashion. Therefore, we respectfully request that you be lit up in red on **November 22, 2026** to raise awareness for chromosome 22q11.2 deletion and duplication syndromes. Questions? Please contact the International 22q11.2 Foundation, Inc. at 001.877.729.1849 or info@22q.org. Thank you in advance for your kind consideration.

The International 22q11.2 Foundation, Inc.
PO Box 532
Matawan, NJ 07747, USA
<https://www.22q.org/>

[Lighting Request Letter](#)



22q at the Zoo Worldwide Awareness Day Sunday May 17th, 2026

Save the date for the 15th Annual 22q at the Zoo – Worldwide Awareness Day, which will take place on **Sunday, May 17th, 2026**. It is an opportunity for families, friends and professionals to socialize, network and raise public awareness of 22q11.2 syndromes. See the 22q at the Zoo photos from [2025](#) | [2024](#) | [2023](#) .

The [list of participating cities](#) will be updated as new information becomes available.

If there were no 22q at the Zoo events in your area in 2025, you can host one in 2026! Please visit the [Host a 22q at the Zoo Event](#) section on our website for more information. We even have an event planner letter ready for you! No zoo? No problem. Consider gathering at a park, a farm, or even an aquarium.

If you have any questions, please email us: info@22q.org. Thank you.



Pre-order your Zoo Day t-shirts on our [SHOP page](#).

Are you the **coordinator** of your local 22q at the Zoo event?

Please email info@22q.org:

- Your **name**
- The name of your **city**
- The name of your **zoo** (or meeting location)
- A way for the participants to **contact** you (e.g. email, social media page etc.)

We will add your location to our [list of participating cities](#).

Vaccination Recommendations for Individuals with 22q11.2 Differences

Vaccine Basics

Check out the updated info sheet on [Vaccination in Health Conditions Explained](#) to find out more about how vaccines work and the various types of vaccines.

Vaccine Safety

Scientific evidence shows that vaccines do not cause autism.

Vaccines are tested carefully before use and checked for safety even after approval.

Don't let false information stop you from getting vaccinated.

Vaccines keep everyone safe.

Vaccine Access

Even though the CDC no longer recommends certain vaccines for American children, these vaccines are still available to them. As long as the healthcare provider and the caregiver agree that the child should receive the vaccine(s), private and public insurance in USA are still required to cover the full costs, with no out-of-pocket costs to families.

Vaccination is a safe and effective way to teach our immune system how to fight dangerous pathogens without actually having the infection. This strategy has been a medical practice since the 1500s and continues to protect us from severe illness and death from over 20 diseases worldwide.

In January 2026, USA's Centers for Disease Control and Prevention (CDC) reduced the number of vaccines suggested for American children. However, **CDC's smaller set of recommended vaccines does NOT provide enough protection.** Therefore, the International 22q11.2 Foundation is providing recommendations for individuals with 22q11.2 deletion syndrome (22q11.2DS) and 22q11.2 duplication syndrome (22q11.2DupS). The sources of these recommendations are:

- [The Immune Deficiency Foundation](#)
- [The American Academy of Pediatrics \(AAP\)](#)

The recommendations have been reviewed and endorsed by our Foundation's [Medical Advisory Board](#) and are applicable as of February 2026. If changes are needed, our Foundation will announce them via our newsletter, social media, website, and email.

Vaccination Recommendations from the International 22q11.2 Foundation

It is recommended that:

- **Individuals with 22q11.2 deletions or duplications** receive vaccines included in the [American Academy of Pediatrics \(AAP\)](#) schedule that their **healthcare providers**, in consultation with their **immunologist**, recommend they receive, even if they may have decreased vaccine responses. Most individuals with 22q11.2 differences can receive vaccines according to the AAP schedule.
- **All individuals with 22q11.2 differences receive an immunological assessment** to see if they can receive these **live attenuated vaccines**: chickenpox (varicella); Measles, mumps, rubella (MMR); Rotavirus; Smallpox; Yellow fever; Bacille Calmette-Guérin (BCG) vaccine (for tuberculosis); and Flu mist;
- **Family members and close contacts** of individuals with 22q11.2 deletions or duplications receive vaccines included in the [American Academy of Pediatrics \(AAP\)](#) schedule that **their healthcare providers recommend they receive**. This decreases the chances that the person with a 22q difference comes into contact with a vaccine-preventable infectious disease.

Note: People on immunoglobulin replacement infusions usually have a modified vaccine schedule.

Meet Dougie

Tell us about yourself... Hi, my name is Dougie Bedinger III, and I'm 15 years old. I was born in Joliet, Illinois. My childhood was scary at first because I had heart surgery and had to have lots of doctor's appointments. But my childhood was also beautiful because the world is so great. I also get to play baseball and do what I love.

When were you diagnosed? My mom and dad told me I was diagnosed with 22q deletion when I was a baby. They found out right after my first heart surgery when I was only 10 days old. Even though I was so little, that moment became the start of my journey with 22q, and it's something that has shaped who I am today.

Tell us a little about school for you... any challenges posed by 22q? How did you overcome them? School was very hard for me, and I often felt embarrassed to be there. I also have autism, which makes social situations and conversations difficult to understand. I get confused easily, so most of the time I just tried to blend in and not be noticed.

Even though it was challenging, I kept going. I learned to push through the hard days, and over time I found ways to cope by observing others, doing my best, and not giving up on myself.

What types of activities did you do growing up? Growing up baseball has always been a big part of my life. I play travel baseball for Rhino Baseball, which is one of the highest levels you can compete at, and it has taught me hard work, focus, and teamwork.

Outside of baseball, I enjoy dirt racing, weightlifting, playing video games, watching YouTube, and hanging out with my friends. All these activities help me stay balanced and give me time to relax and have fun.



What are you most proud of? I'm most proud of being picked to design Wilson Baseball's first ever first baseman glove for the Autism Speaks spring line of 2025. It was so much fun! I'm also most proud that I'm alive.

Any advice you'd like to share to children growing up with 22q? Growing up with 22q, the challenges are real but so is our strength. Life gets better and you can accomplish big things.

What are your goals for the future? To play professional baseball and make it to the big leagues. I'd also love to get into dirt car racing and see where that road takes me. Currently I am a sophomore at Coal City High School.

This article was originally [published](#) on the website of the International 22q11.2 Foundation on December 5, 2025.

More Articles Featuring Dougie

- [Dougie Bedinger using Autism journey to inspire others by playing the game he loves most](#) – CBS News, Chicago, July 30, 2025
- [Handling Curveballs: Dougie Bedinger takes autism to the mound](#) – Autism Speaks

To read more inspirational stories, please visit: <https://22q.org/inspirational-stories/>

The International 22q11.2 Foundation would love to hear personal stories about friends and family persevering and thriving with 22q! Please download this [questionnaire](#) and email your info to us at info@22q.org, along with two high quality photos, and we will contact you for more info! We look forward to hearing from you!

How 22q11.2 Deletions and Duplications Happen

In genetics, **deletion** means a piece of DNA is missing. In individuals with 22q11.2 deletion syndrome, a segment of DNA from one of the two copies of chromosome 22 is missing. Since **DNA sequences encode genes**, a person with the deletion experiences the loss of 1 of 2 copies of ~50 genes that direct how the body is formed and may function.

On the other hand, **duplication** means a piece of DNA is repeated so that there is an extra piece of DNA. In individuals with 22q11.2 duplication syndrome, a segment of DNA from one of the two copies of chromosome 22 is repeated. This means the person has 3 copies (rather than 2) of about 50 genes that direct how the body is formed and may function.

But how do the deletions and duplications on chromosome 22 happen? Here is a simplified explanation.

In the cells that are getting ready to become eggs or sperms, chromosomes pair up. A copy of chromosome 22 would pair up properly with the other copy of chromosome 22 (Figure 1a).

The paired-up chromosomes often exchange small sections (Figure 1b). This is a normal process called **homologous recombination**. Some eggs or sperms will eventually carry chromosomes with new combinations of DNA (Figure 1c).

However, the q11.2 section of chromosome 22 contains a few low copy repeats (LCRs). These are sequences that look very similar to one another. **An LCR can accidentally mispair with the wrong LCR on the partner chromosome (Figure 2a) or on the same chromosome (Figure 2b).** This type of exchange between similar DNA sequences (but not between the same genes) is called **non-allelic homologous recombination**.

Since the chromosomes are mispaired, the **exchanges will likely result in a loss (a deletion) or a gain (duplication) in DNA**. The individuals who receive the deletion will be missing some genes, while those who receive the duplication will have too many copies of some genes.

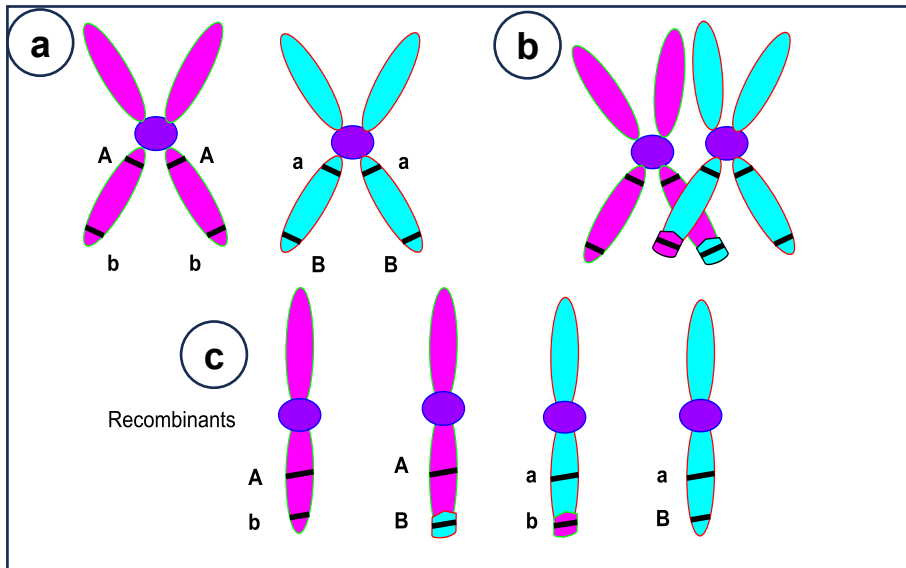
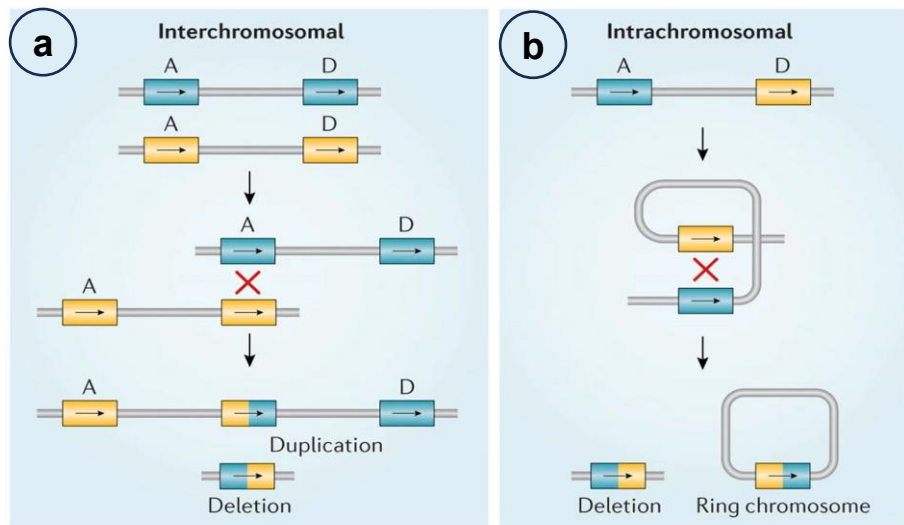


Figure 1: Homologous recombination. Image adapted from [Wikimedia.org](https://www.wikimedia.org)



Nature Reviews | **Disease Primers**

Figure 2: Non-allelic homologous recombination (NAHR).

Image reused with permission from the authors (copyright holder) of:

[22q11.2 Deletion Syndrome in Offspring Conceived via Assisted Reproductive Technology Versus Spontaneously](https://doi.org/10.1038/nrn3112)

Borowka J, Crowley TB, Mani A, Guinta V, McGinn DE, Wang B, Green A, Rockart L, Tran O, Emanuel BS, Zackai EH, Dugoff L, Valverde K, McDonald-McGinn DM. *Genes (Basel)*. 2026 Jan 6;17(1):68. doi: 10.3390/genes17010068. PMID: 41595488; PMCID: PMC12840787.

22q11.2DS in Children Who Were Conceived with the Help of Assisted Reproductive Technology

[22q11.2 Deletion Syndrome in Offspring Conceived via Assisted Reproductive Technology Versus Spontaneously](#)

Borowka J, Crowley TB, Mani A, Guinta V, McGinn DE, Wang B, Green A, Rockart L, Tran O, Emanuel BS, Zackai EH, Dugoff L, Valverde K, McDonald-McGinn DM. *Genes* (Basel). 2026 Jan 6;17(1):68. doi: 10.3390/genes17010068. PMID: 41595488; PMCID: PMC12840787.

Assisted reproductive technology (ART) is fertility treatment that involves the handling of eggs or embryos outside of the human body. The goal is to generate embryos that can be transferred into a uterus and develop into babies. However, embryos are very sensitive to the environment. Differences in temperature, oxygen levels, acidity, and other aspects can affect whether an embryo can survive during the ART process. There have been conflicting reports on whether ART increases the risk of developing deletions and duplications in human chromosomes.

Researchers wanted to find out if ART increased the risk of 22q11.2DS. Specifically, they examined:

1. Whether the rate of ART conception was higher among people with 22q11.2DS compared to the general U.S. population;
2. Whether there were any differences in the health status among babies conceived via ART compared to those conceived naturally;
3. Whether the 22q11.2 deletions sizes were different among people conceived via ART compared to those conceived naturally.

Study Population

- 1169 patients at the 22q and You Center at the Children's Hospital of Philadelphia (CHOP), USA

Methods

- Reviewed medical records of the patients
- Collected data on:
 - Conception and pregnancy history
 - Newborn health status
 - Admission to neonatal intensive care unit (NICU)
 - Congenital heart diseases

Findings

- 30/1169 (2.57%) of patients with 22q11.2DS were conceived via ART. This is similar to the rate (2.3%) in the US general population.
- The ART group and the naturally-conceived group had similar:
 - Distribution of 22q11.2 deletion sizes
 - Frequency of congenital heart diseases
- Compared to the people in the naturally conceived group, those in the ART group:
 - Were diagnosed with 22q11.2DS at a younger age (average 1.59 years vs. 2.58 years)
 - Had parents who were older
 - Were more likely to be admitted to the NICU (70.0% vs. 25.9%)
- Compared to the people in the naturally conceived group, those in the ART group had a higher rate of pre-term birth and lower birthweight. However, after accounting for factors that influence pregnancies (e.g. having too much amniotic fluid, having multiple babies at the same time, and/or having congenital heart diseases), the ART group in fact had similar rates of pre-term birth and low birthweight compared to the naturally-conceived group.

Main Message

- The occurrence of 22q11.2 deletions is not due to the use of ART, but is due to a random event (see previous page). **A baby conceived through ART does NOT have an increased risk of 22q11.2DS.**
- Potential parents who wish to use ART need to be aware of the **increased risk of preterm birth, lower birth weight, and higher chance of NICU admission.**

Recent research findings on

Chronic Inflammatory Arthritis and 22q11.2DS

[Chronic inflammatory arthritis in 22q11.2 deletion \(DiGeorge\) syndrome: a multicentric study.](#)

Liebling E, Freychet C, Guarneri V, Jelusic M, López JA, Kallinich T, Montin D, McCann LJ, Bader-Meunier B, Crowley TB, Lemelle I, McDonald-McGinn D, Serrano M, Stephan JL, Azzari C, Simonini G, Giani T.

Orphanet J Rare Dis. 2025 Nov 24;20(1):603. doi: 10.1186/s13023-025-04088-2. PMID: 41287064; PMCID: PMC12642041.

Background Information

A **joint** is the place where two bones meet. Each person has hundreds of joints. **Arthritis** is the inflammation of the joint.

Inflammation is part of the immune system's normal response to injuries and infections. The immune system directs cells and cytokines to promote healing and to battle the invaders. The typical signs of inflammation are **pain, swelling, heat, and redness**, which usually lasts for a few hours to a few days. The inflammation usually goes away when the injury is healed or when the invaders are under control. If the inflammation persists, the person has **chronic inflammation**. Long term uncontrolled inflammation can damage healthy parts of the body and cause more medical problems.

Juvenile idiopathic arthritis (JIA), also called juvenile rheumatoid arthritis (JRA) happens when the immune system mistakenly attacks the tissues and fluids inside the joints. JIA occurs in 0.0038 to 0.4% in the general population and ~2% of children with 22q11.2DS. (Chronic inflammatory arthritis happens in 1.5 to 3.7% in children with 22q11.2DS.) The symptoms of JIA include joints that are swollen, stiff, warm, painful, and hard to move. JIA is often associated with **uveitis**, an autoimmune inflammatory condition affecting the eye.

Chronic inflammatory arthritis seems to emerge as part of 22q11.2DS, affecting 1.5 to 3.7% of children with this condition. Researchers wanted to learn more about chronic inflammatory arthritis and see if it is similar to juvenile idiopathic arthritis (JIA).

Study Population

- 21 girls + 9 boys with 22q11.2DS and chronic inflammatory arthritis
- Origin: USA, France, Italy, Croatia, UK, Spain, Germany
- All have a lab confirmation of the genetic diagnosis and at least 2 major features of 22q11.2DS related to the heart, face, immune system, palate, and calcium levels.

Methods

- Reviewing medical records of the patients

Findings on Chronic Inflammatory Arthritis in Children with 22q11.2DS

- Diagnosed between 1 and 12 years, mainly before 5 years old
- In half the cases, multiple joints were affected
- Blood test results showed an increase in inflammation
- The most commonly affected joints were the knees and ankles
- Patients were often treated with medications that modified immune responses: e.g., [corticosteroids](#), [Disease-Modifying Antirheumatic Drugs \(DMARDs\)](#) such as methotrexate and biologics
- Early use of biologics helped control the arthritis better
- Even though these patients needed to take medications that change their immune responses, their rate of infections did not increase
- Chronic inflammatory arthritis lasted over 10 years in most cases
- By the time the arthritis was under control, the damage to the joints were visible on x-ray
- In many cases, patients who got better from the arthritis needed to continue to take medications to prevent it from getting worse

Main Message

Chronic arthritis is not so uncommon in 22q11.2DS, and it seems to have a distinct presentation. Compared to JIA, chronic inflammatory arthritis in 22q11.2DS:

- Starts at an earlier age
- Affects more joints
- Is more severe and prolonged
- Needs more treatment (including those that are less conventional)
- Is less likely to include uveitis (an autoimmune condition in the eye)
- Leads to joint damage more frequently

Eyes Series Now Available

Our **eyes** are complex organs that process the incoming light to help us see. When parts of the eyes do not work well or did not develop fully, we may not be able to see properly. The “**Eye Series**” in the “**Health Conditions Explained**” section of our website provides explanations on the common and/or significant eye problems in individuals with 22q11.2 deletion and duplications. Special thanks to Dr. Brian Forbes, Attending Surgeon, Division of Ophthalmology, Children’s Hospital of Philadelphia (CHOP) and Joanne Loo, Programmatic and Educational Tool Developer of our Foundation.

- [Eye issues in 22q Differences](#)
- [Introduction to the Eye](#)
- [Refractive Errors](#)
- [Reduced Vision](#)
- [Strabismus \(Misalignment of the Eyes\)](#)
- [Sclerocornea](#)
- [Ptosis \(Droopy Eyelid\)](#)

Be sure to check out all the topics in the “**Health Conditions Explained**” section of our website!

- [Heart Series](#)
- [Dental Series](#)
- [Palate Series](#)
- [Eye Series](#)
- [Mental Health Series](#)
- [Speech Series](#)
- [Sleep Series](#)
- [22q Glossary \(4th ed.\)](#)
- [Gastrointestinal \(GI\) Series](#)
- [Immune System Series](#)
- [Brain and Nerves Series](#)

Disclaimer: This information is brought to you by the International 22q11.2 Foundation for educational purposes only. It is not intended to be taken as medical advice. If you have concerns, please talk to your healthcare provider.

Clinical Recommendations Documents

Updated clinical practice recommendations for managing **children** with 22q11.2 deletion syndrome

- [English \(Original\)](#)
- [French – Français](#)
- [Spanish – Español](#)
- [Simplified Chinese – 简体中文](#)

Updated clinical practice recommendations for managing **adults** with 22q11.2 deletion syndrome

- [English \(Original\)](#)
- [French – Français](#)
- [Spanish – Español](#)
- [Traditional Chinese 繁體中文](#)

Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions – English

Speech-Language Disorders in 22q11.2 Deletion Syndrome: Best Practices for Diagnosis and Management – English

Expert healthcare providers are currently preparing a document that will provide detailed information on features associated with the chromosome 22q11.2 duplication syndrome (22q11.2DupS).

In the interim, these experts are using the same healthcare guidelines prepared for the 22q11.2 deletion syndrome, as the associated features are quite similar, just with lower frequency.

Our Foundation will be in touch as soon as the new paper for the 22q11.2 duplication syndrome is published. Thank you for your patience and understanding.

Donate Now

Our mission: to improve the quality of life for individuals affected by chromosome 22q11.2 differences through family and professional partnerships.



What would we do with the funds:

- Support Research
- Support family conferences
- Support awareness
- Support Newborn Screening
- Support and raise awareness for 22q!

Your support makes a difference!

There are so many options for **Team 22q Fundraising**! Take part in one of the Foundation's event or create your own.

Please visit the **Donate** page on our website for information on donating online, by mail, or via other methods.

Please also **Shop** on our webstore.

For more information, please visit our website at **www.22q.org** or email us at **info@22q.org**.

Team 22q Fundraising

- **Tell 22 Friends** about 22q
- Become a **monthly donor**
- Be a 22q Citizen Journalist and share your event on social media!
- Plan a **22q at the Zoo** event
- Plan a **22K for 22q** event (It can also be 2.2K!)
- Create Your Own Event or Fundraiser Contact us at **info@22q.org**

Thank you!

Connect With Us



The mission of the **International 22q11.2 Foundation** is to improve the quality of life for individuals affected by chromosome 22q11.2 differences through family and professional partnerships. This information is brought to you by the Foundation for educational purposes only. It is not intended to be taken as medical advice. If you have concerns, please talk to your healthcare provider.

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