



International  
22q11.2 Foundation

# Newsletter September 2026

We hope you and your family had a great summer.

We are absolutely delighted to share that **Carol Cavana**, the Administrative Director of our Foundation, was honored with the **Clodagh Murphy Unsung Hero Award** at the 14<sup>th</sup> Biennial International 22q11.2 Scientific Meeting in July. You can read more about her award and other aspects of the conference in this newsletter. We also bring you recent research findings, vaccination reminders, new info sheets in the Puberty Series, and more. Remember to check out Tenzin's story and save the date for upcoming events.

Happy Reading!

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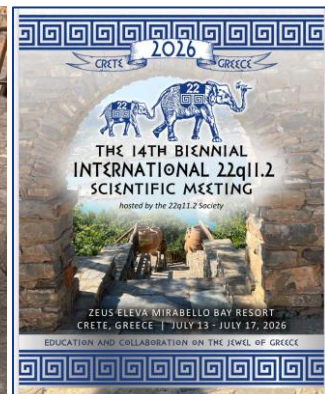
## Successful Conference

The International 22q11.2 Foundation is incredibly grateful to be part of the **14<sup>th</sup> Biennial International 22q11.2 Scientific Meeting** from July 13 to 17 on the island of Crete in Greece. Our representatives were part of the Family Voices Panel (see p. 2).

The meeting was a wonderful opportunity for researchers, healthcare providers, advocates, and parent organizations to unite with one shared goal: improving the lives of individuals and families affected by 22q11.2 deletion syndrome (22q11.2DS). The collaboration, innovation, and commitment to advancing research, clinical care, and family support are truly inspiring.

This international conference has been taking place every 2 years since 1998. This year, attendees came from 20 countries to immerse themselves in everything 22q for 4 days. You can browse the topics in the **[Meeting Program](#)**. As the attendees shared their latest findings and solved problems together, they also built new working relationships by participating in the social events of this conference. All of this will contribute to fruitful discoveries that will benefit individuals with 22q11.2DS and their families.

Please check out the photos and award news on pages 2 to 5 of this newsletter. We look forward to the next conference in France in 2028!



# Family Voices Panel at the Conference

At the 14<sup>th</sup> Biennial International 22q11.2 conference, leaders of a number of organizations led the Family Voices session. The main message was **what individuals with 22q11.2DS and their families want healthcare professionals to know**. The panel included:

- Carol Cavana and Debbie DeLoach (International 22q11.2 Foundation)
- Kim van Bekkum and Marc van Hout (Stichting Steun 22Q11)
- Julie Wootton (Max Appeal, UK)
- Vesna Vujicic (22q et YU, Serbia)

Images:

- Right: Summary of the discussion (originally published as Abstract #143 on p. 188 of the [conference program](#));
- Bottom Left: (from left) Julie Wootton, Kim van Bekkum, Carol Cavana, Vesna Vujicic, and Debbie DeLoach;
- Bottom Right: Marc van Hout

Abstracts - Platform



143: Family voices

What do families/caregivers/individuals with 22q want you to know?

- 22q is common but the diagnostic odyssey is real
- Most people have never heard of 22q
  - What can we do to create change?
- Early childhood is difficult
  - Especially feeding and swallowing problems because the parent who is unable to feed their child feels like a failure; nasal regurgitation is not normal
- Transition to adolescence and adulthood is harder still
- Coordinated multidisciplinary care is limited
  - By geography
  - By healthcare systems
  - By internet providers
    - How do we gain access and how do we choose?
- Waiting for the other shoe to drop in the form of psychiatric illness is the most challenging
  - Behavioral health specialists are few and far between
  - Formal neuropsychological testing is necessary to help with short- and long-term planning
    - But it can be expensive or nonexistent
  - Treatments are confusing
- A diagnosis in an adult is both welcome and perplexing
  - Causing some people to spiral
- We are exhausted – mentally and physically
- We want to help – with research and fundraising but we are not sure how
- We are a global community willing to work together, with the power to unlock many doors
  - But our goals differ by the age of our children & there are many groups with divergent agendas
    - Including families with the duplication; distal deletions and duplications; dual diagnoses such as TANGO2 – who all need and deserve our help
      - How do we serve everyone?
      - How do we keep up?
  - If we can develop a common goal and the resources to tap into that potential, we can be successful
    - HELP US TO HELP YOU

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# Carol Cavana Honored with the Clodagh Murphy Unsung Hero Award

The **Clodagh Murphy Unsung Hero Award** is presented at the Biennial International 22q11.2 Scientific Meeting to recognize an individual whose extraordinary dedication has made a lasting impact on the 22q11.2 community. The award honors:

- Commitment through community service;
- Selfless devotion to education, awareness, healthcare advances, and research;
- Collaboration and inclusivity across international 22q11.2 organizations and the medical and research communities; and
- Meaningful national and international impact on individuals with chromosome 22q11.2 differences and their families and caregivers.

At the **2026 Biennial International 22q11.2 Scientific Meeting in Crete, Greece**, the Clodagh Murphy Unsung Hero Award was proudly presented to **Carol Cavana**, a truly deserving recipient whose commitment to the 22q community has spanned nearly three decades.

Carol's journey began when her son, **Louis, was born in 1998**. Following his diagnosis of 22q, Carol devoted herself to learning, advocating, and finding the resources Louis needed as he navigated procedures, surgeries, education, and everyday life. What began as a mother's determination to help her son soon grew into a lifelong commitment to helping families throughout the 22q community.

In 2003, Carol became a **founding member of the U.S.-based International 22q11.2 Deletion Syndrome Foundation, Inc.** and was the Chair from 2010 to 2012. More than two decades later, she continues that work as the Foundation's **Administrative Director**, playing an integral role in its growth, outreach, and impact locally and around the world.

Throughout the years, Carol has been instrumental in bringing the 22q community together through **events and awareness initiatives including 22K for 22q and 22q at the Zoo Worldwide Awareness Day**, which has united families around the world for 16 years.



**Carol Cavana** (center) celebrates receiving the **Clodagh Murphy Unsung Hero Award** with Debbie DeLoach (left) and Prof. Donna McDonald-McGinn (right) on July 14<sup>th</sup>, 2026

Carol's impact cannot be measured by events alone. It can be found in the countless **families** she has supported, the **connections** she has helped create, the **awareness** she has raised, and the **international community** she has worked tirelessly to strengthen. She has rallied not only the worldwide 22q community, but also included her own family and friends around a cause that has remained at the center of her life.

There is rarely a day that goes by when Carol isn't doing something to support, encourage, educate, or connect someone within the 22q community. Much of that work happens quietly and behind the scenes, which makes the title **"Unsung Hero"** especially fitting.

**Congratulations, Carol, on receiving the 2026 Clodagh Murphy Unsung Hero Award.** Your decades of dedication, compassion, and service have touched more lives than you may ever know. The International 22q11.2 Foundation and the worldwide 22q community are stronger because of you, and we are incredibly grateful for all you have done, and continue to do, for our families.

# Major Awards For Researchers

## The Angelo DiGeorge Medal of Honor

- Sixto Garcia-Minaur, MD (Madrid)
- Alexander Damian Heine-Suner, PhD (Palma de Mallorca)



The Angelo DiGeorge medal recognizes an outstanding contribution to our understanding and/or treatment of the 22q11.2 deletion syndrome, and was inaugurated in 2010 to commemorate the life and work of Dr. Angelo DiGeorge.

Photos on the left: DiGeorge Medals for the 2026 recipients.

Photo on the right: (From left to right) Dr. Anne Bassett, Dr. Sixto Garcia-Minaur (award recipient), Prof. Donna McDonald-McGinn, Prof. Alexander Damian Heine-Suner (award recipient), and Prof. Ann Swillen.



## The Peter Scambler Invited Lecture Award

- Joris R. Vermeesch, PhD (Leuven)

The Peter Scambler Invited Lecture, inaugurated in 2022, is a featured lecture at the Biennial International 22q11.2 Scientific Conference in honor of Founding Trustee and inaugural Chair (2013-2019), Dr. Peter Scambler. The lecture, awarded by Dr. Peter Scambler and the Trustees of the 22q11.2 Society, kicks off the scientific program at the conference.

Photo on the right, from left to right: Dr. Anne Bassett, Dr. Peter Scambler, Prof. Joris R. Vermeesch (award recipient), and Prof. Donna McDonald-McGinn.



For previous recipients, please visit the [Awards](#) page of the 22q11.2 Society's website.

**Congratulations** to the recipients of these major awards as well as the participants who won **Top Presenter Awards** in their sessions!

# Reminder: 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 USA, there is currently conflicting guidance on the administration of vaccines. **In order to offer evidence-based information and enough protection against infections, the International 22q11.2 Foundation is providing vaccination recommendations for individuals with 22q11.2 deletion syndrome (22q11.2DS) and 22q11.2 duplication syndrome (22q11.2DupS).** This set of recommendations was first published in our newsletter in March 2026. 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 have been applicable since 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.

# Vaccination Schedule from the American Academy of Pediatrics (USA)

Please **download the full document** (18 pages).

- The images on the right shows two of the main tables from the vaccination schedule from American Academy of Pediatrics (AAP) in the USA.
- **Most individuals with 22q11.2 differences can receive vaccines according to the main AAP schedule** (Table 1 on p. 2 of [pdf](#)).
- Individuals with 22q11.2 are very diverse in terms of their immune systems. It is important to **evaluate all children with 22q11.2DS immunologically at diagnosis to see if they can receive live attenuated vaccines**.
- The vaccination schedule from the American Academy of Pediatrics is tailored to families in the USA. Different countries have different vaccination schedules. Please consult the vaccination schedule that is endorsed by medical professionals in your country.

## Vaccination for People with Low T Cells

People with very low T cells (CD4 <400 cells/mm<sup>3</sup> or CD8 <200 cells/mm<sup>3</sup>) should **not** receive live attenuated vaccines.

➤ MMR (measles, mumps, rubella)

➤ Bacille Calmette-Guérin (BCG) vaccine (tuberculosis)

➤ Chickenpox (varicella)

➤ Nasal mist type of flu vaccine

➤ Smallpox

➤ Yellow fever

## Main Message

**All individuals with 22q11.2 differences should receive an immunological assessment.**

- Those with very low T cells (CD4 <400 cells/mm<sup>3</sup> or CD8 <200 cells/mm<sup>3</sup>) should **not** receive live attenuated vaccines.
- Everyone else (patients, family members, and close contacts) are recommended to receive vaccines according to the vaccination schedule endorsed by medical professionals (e.g. the AAP in the USA) in your country.

Table 1: Main Vaccination Schedule

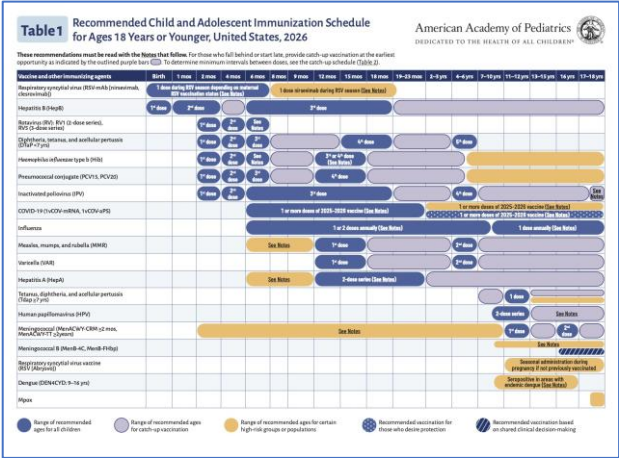
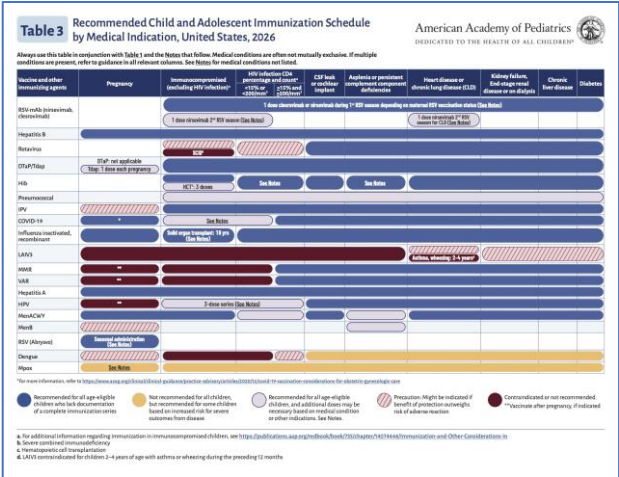


Table 3: Vaccination Schedule by Medical Condition (For babies with very low T cells (CD4 <400 cells/mm<sup>3</sup> or CD8 <200 cells/mm<sup>3</sup>), see the third column for “Immunocompromised”)



## Vaccination Schedules

- [European Union](#)
- [Pan American Health Organization](#)
- [American Academy of Pediatrics](#)
- [World Health Organization \(WHO\)](#)

# Puberty Series for 22q11.2 Differences

We have now completed all 8 info sheets for the Puberty Series for 22q11.2 Differences. This newest series in [Health Conditions Explained](#) talks about body changes, behavioral challenges, and sexual health concerns that teenagers may have. We are also providing links to additional resources to help parents talk to their teens about various issues.

Many thanks to Joanne Loo, PhD, Programmatic and Educational Tool Developer and Natalie Blagowidow, MD, Obstetrician/Gynecologist for developing and reviewing the Puberty Series. We also thank Samantha D'Arcy, MHSc, RD, Registered Dietitian; Nikolai Gil D. Reyes, MD, Neurologist; and Maude Schneider, PhD, Psychologist and Psychotherapist for reviewing the specific subtopics.

Here are the 3 topics published in May:

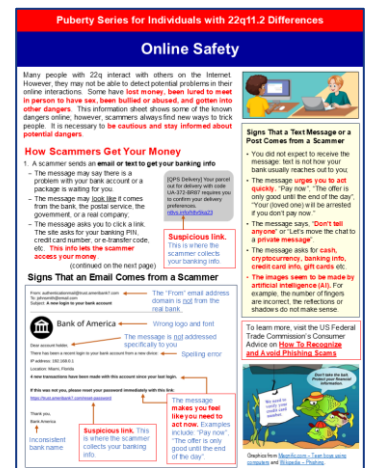
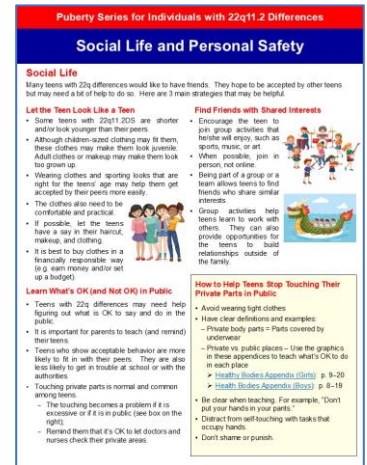
- [Girls' Body Changes During Puberty](#)
- [Boys' Body Changes During Puberty](#)
- [Staying Clean and Healthy](#)

Here are the 5 new topics published in August:

- [Social Life and Personal Safety](#)
- [Online Safety](#)
- [Behavior Issues and Coping Strategies](#)
- [Sexual and Reproductive Health for Girls and Women](#)
- [Sexual and Reproductive Health for Boys and Men](#)

Sexual and reproductive health may not be a comfortable topic, and it may be forgotten in the midst of other health issues. However, it is important to provide positive and health-based support and balance sexual wants, needs, and concerns.

- in "Sexual and Reproductive Health" (for both genders)



Be sure to check out all the topics in the ["Health Conditions Explained"](#) section of our website!

- Heart Series
- Mental Health Series
- Gastrointestinal (GI) Series
- Dental Series
- Speech Series
- Immune System Series
- Palate Series
- Sleep Series
- Brain and Nerves Series
- Eye Series
- 22q Glossary (4<sup>th</sup> ed.)
- Eye 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.

# Research News: Use of SSRIs in People with 22q11.2DS

## What are SSRIs?

**Serotonin** is a chemical messenger in the brain. It regulates appetite, mood, sleep, etc. Usually, after serotonin delivers the message, it gets re-absorbed by brain cells.

**Selective Serotonin Reuptake Inhibitors (SSRIs)** are medications that prevent serotonin from being re-absorbed by brain cells. The serotonin can then function for longer.

SSRIs are commonly used to treat mental health conditions, e.g., mood disorders and anxiety disorders (including obsessive compulsive disorder (OCD)). They usually take a few weeks to work, and they can also have various side effects. Check with your healthcare provider if you have any concerns about SSRIs.

## [Multicenter retrospective study on perceived effectiveness, reported side effects, and cognitive outcomes of SSRIs in 22q11.2 deletion syndrome.](#)

Latrèche C, Mancini V, Dvojakovska M, Kushan L, Mchangama F, Tairi F, Cohen T, Spapens J, Reijn L, Díaz-Caneja CM, Acheampong H, De Troch L, Vergaelen E, Vogels A, Swillen A, Vingerhoets C, Boot E, Arango C, Velders F, Fiksinski A, van Amelsvoort T, Gothelf D, Bearden CE, Chaumette B, Schneider M, Eliez S. *Eur Child Adolesc Psychiatry*. 2026 Aug 7. doi: 10.1007/s00787-026-03155-8. Epub ahead of print. PMID: 42565881.

See also: [Effectiveness, side effects, and cognitive outcomes of SSRIs in 22q11DS \(Presentation slides\)](#) by Caren Latrèche

Many individuals with 22q11.2DS take SSRIs to manage their mental health problems. At the same time, many of them have lower IQ scores that further decline over time. Researchers from 1 American city and 8 European cities jointly studied:

1. Are SSRIs safe and effective for people with 22q11.2DS?
2. Do SSRI treatments affect how people's IQ changes over time?

## Some limitations of this study

Some records and ratings were processed differently in the 9 cities involved in this study.

The low rates of reported side effect may be due to the dropping out of people who had effects.

Many other factors can influence the use and the effectiveness of SSRIs.

## 1. Observing the safety and effectiveness of SSRIs in 22q11.2DS

### Participants

- 190 people (6 to 56 years), confirmed 22q11.2DS + used SSRI;

### Methods

- Checked medical records on why the person was taking an SSRI
- Asked the person / caregiver to rate the effectiveness and side effects of SSRI on the person

### Results: Safety and effectiveness of SSRIs

- 136 people had info on why they were taking SSRIs. The top 3 reasons were mood disorders (45%), anxiety disorders (35%), and combined mood and anxiety disorders (14%).
- 40 people had info on side effects. 75% of them had no side effects. Others experienced weight gain (13%), drowsiness/ sleepiness (10%), and gastrointestinal symptoms (2%)
- 86 people rated the effectiveness of the SSRI they took. 29% – very effective, 42% – effective, 8% – moderately effective; 12% – slightly effective, and 9% – ineffective

## 2. Tracking IQ changes in people who did and did not use SSRI

### Participants

- 314 people (4 to 34 years), confirmed 22q11.2DS, with or without the use of SSRI;
- 101 of these individuals were SSRI treated.

### Methods

- Tested IQ (using Wechsler Intelligence Scale) every ~3.67 years
- Checked IQ test results for improvement/decline
- Compared results between people who used and did not use SSRI
- Checked if psychostimulants made any difference

### Results: IQ in people treated with SSRI vs. no SSRI

- SSRI-treated: IQ was stable or modestly improved
- No SSRI: IQ decreased slightly over time
- IQ differences appeared 1-3 years after the start of SSRI treatment
- Longer SSRI use was related to better IQ trajectory

### Results: Did psychostimulants make a difference

- SSRI and psychostimulant: IQ improved
- SSRI but no psychostimulant: IQ was stable
- No SSRI but had psychostimulant: IQ decreased

## Main message

SSRIs are safe and effective for people with 22q11.2DS. The continued use of SSRIs is associated with stable or improved IQ over time. The use of SSRIs together with psychostimulants is associated with better IQ improvements. **Early screening for anxiety, mood, and ADHD allows for timely treatment that is helpful for thinking/learning and mental health.**

# Research News: 22q11.2 Duplication Syndrome: Findings from 691 Individuals (679 from literature +12 newly-reported)

## Microduplication Syndrome: A Review of the Literature and 12 New Cases.

Bisba M, Louizou E, Vittas S.

Chromosome 22q11.2 Genes (Basel). 2026 Jul 22;17(7):844. doi: 10.3390/genes17070844.

Studies on 22q11.2 duplications syndrome (22q11.2DupS) are relatively rare and small. Recently, a team from Greece published their findings on 12 individuals with this condition. They combined the findings with those from all relevant reports that were previously published. The result is a big picture of 22q11.2DupS gathered from 691 individuals.

### **Methods – Part 1: Studying 12 individuals who were newly-diagnosed with 22q11.2DupS**

- Location: a commercial laboratory in Greece;
- Method of genetic testing: [chromosomal microarray analysis \(CMA\)](#);
- People being tested: 5 fetuses and 7 babies who were referred by doctors;
- Medical records collected.

### **Methods – Part 2: Studying 47 published reports on 679 individuals with 22q11.2DupS**

- Searched for reports (up to April 2025) on 22q11.2DupS in PubMed database;
- Only included reports where the patients' 22q11.2DupS results were confirmed by genetic testing and whose clinical info was available.

## **Main Results (Combined 12 + 679 = 691 individuals with 22q11.2DupS)**

### Why Was Testing Done?

- Before birth:
  - Abnormal ultrasound findings (46.4%)
  - Screening due to advanced maternal age, family history (25.0%)
  - Abnormal biochemical findings (20.5%)
  - Heart defects (3.6%)
  - [Noninvasive prenatal testing \(NIPT\)](#) (3.6%)
  - Other issues (0.9%)

### What Clinical Findings Were Reported After Birth?

After birth:

- Neurodevelopmental disorders (43.6%)
- Heart defects (25.4%)
- Unusual facial features (9.1%)
- Eye findings (9.0%)
- Other / Normal / Unknown (12.9%)

### Was the Duplication Inherited or New?

- Inheritance pattern:
  - From mother (14.3%)
  - From father (11.9%)
  - From both parents (0.2%)
  - Inherited but pattern not known (10.3%)
  - Duplication is new (13.5%)
  - Inheritance status unknown (49.8%)
- There were no clear association between inheritance pattern and the size of the duplication

### Where Were the Duplications?

- Duplication location:
  - “Typical” or Proximal (LCR22A-D) (57.2%)
  - Distal (LCR22D-H) (12.3%)
- Note: There may be a bias towards the better known “typical” location.

### Comparing 22q11.2 Deletions vs. Duplications

- Some of the medical issues in these conditions are the same. E.g.:
  - Neurodevelopmental disorders
  - Being born with certain heart defects;
- People with 22q11.2DupS tend to have milder forms of medical issues;
- Many body systems may be affected;
- Some people with 22q11.2DupS may not develop medical issues known to associate with the duplication, i.e. they are carriers.
  - Compared to 22q11.2DS, 22q11.2DupS has a higher frequency of carriers.
- Different people with 22q11.2DupS, even those within the same family, can have different combinations of medical issues.
- The most common finding in 22q11.2DupS are neurodevelopmental disorders. E.g. developmental delay, hypotonia.
- Note: There may be a bias towards people with medical issues.

# Clinical Recommendations for 22q11.2DS

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](#)
- [Dutch - Nederlands](#)
- [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 mean time, 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. Thank you for your patience.

## 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 22<sup>nd</sup> (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 Saturday, November 22<sup>nd</sup>, 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 22<sup>nd</sup>, 2026**, take pictures of yourself with the illuminated building and share them on social media.

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

On November 22<sup>nd</sup>, remember to **take photos of the buildings in red**. Please share your photos with us on social media or via email ([info@22q.org](mailto:info@22q.org)).

Please note, by sharing your photos, you grant the Foundation permission to use it.

### 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 swallowing differences, 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 caused it to occur. However, once 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 2018, La Asociación Síndrome 22q11 in Spain launched an awareness campaign entitled "Lucas por el 22q" (Lighting the Night for 22q). Buildings and monuments were illuminated in red on November 22 (22/11 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

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 001.877.739.1849 or [info@22q.org](mailto: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](#)





## Save the Date for 22q & Boo!

### An educational symposium and Halloween party for children

Join the 22q and You Center at Children's Hospital of Philadelphia (CHOP) for some Halloween fun on Sunday, Oct. 18<sup>th</sup>!

Activities for this year's in-person event will include arts & crafts, games, and refreshments, and an educational component.

Costumes are strongly encouraged!

For more information and to register, please visit:

<https://www.chop.edu/events/22q-boo>

**Sunday Oct 18<sup>th</sup>, 2026**

12:00 pm to 3:00 pm EDT

Children's Hospital of Philadelphia  
Abramson Pediatric Research Center, Room 123 A/B/C  
3615 Civic Center Blvd, Philadelphia, PA 19104

Questions?

Please email [22q@chop.edu](mailto:22q@chop.edu).

# Meet Tenzin

Originally published on the Foundation's website on March 25, 2026

My name is Tenzin Dhoundup, and I was born in Himachal Pradesh, India. From the very beginning, my life was a little different. When I was young, my mother was told by a cardiologist that I had a ventricular septal defect and would need ongoing care. My childhood wasn't like most others, but those early challenges helped shape my strength and resilience.

For many years, I didn't fully understand everything I was going through. That changed when I was 17. After experiencing multiple seizures, I was admitted to the hospital for further evaluation. During that time, doctors recommended genetic testing, and I was referred for more specialized care. That's when I was diagnosed with 22q11.2 Deletion Syndrome. It was a lot to take in, but it also gave me answers I had been searching for.

That experience in the hospital changed my life in another important way—it's where I discovered my passion for nursing. Being surrounded by healthcare professionals who cared for me and supported me inspired me to want to do the same for others.

School was not always easy for me. I faced challenges, especially with speech and learning, and I worked with a speech pathologist who made a big impact on my life. She was kind, supportive, and truly cared about me. I also had an Individualized Education Program starting in middle school, and my mother was a strong advocate for me every step of the way. Because of that support, I was able to keep moving forward.

Growing up, I found peace in simple things. I enjoyed running and spending time near rivers. Those moments helped me feel calm and grounded.



Today, I am proud of how far I've come. I completed my training as a Patient Care Technician, and I am working toward going to nursing school. It hasn't been an easy journey, but it has been meaningful, and every step has brought me closer to my goals.

If I could share anything with others growing up with 22q, it would be this: anything is possible if you have aspirations and believe in yourself. I was a very shy kid, but I've learned that you can grow, find your voice, and achieve more than you ever thought possible. You are not alone—there are people who care and a community that supports you.

Looking ahead, my goal is to become a nurse and use my experiences to help others. I want to give back, support patients, and make a difference in their lives—just like others have done for me.

My journey hasn't always been easy, but it has made me who I am today. And I'm proud to keep moving forward.

For more inspirational stories, visit:

<https://22q.org/inspirational-stories/>

## Would you like to share your story?

We all need inspirations every now and then. If you or someone you know is living, and maybe even thriving, with 22q, please share your story!

Please complete this [questionnaire](#) and email your information to us at [info@22q.org](mailto:info@22q.org), along with two, high quality photos, and we will contact you for more information!

# 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



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