International 22q11.2 Foundation

Newsletter March 2025

In this newsletter…

The International 22q11.2 Foundation is celebrating an amazing milestone as we proudly commemorate the 22nd anniversary of our commitment to the global 22q community!

Since our inception in 2003, we have been dedicated to supporting families affected by chromosome 22q differences, beginning with the deletion, and expanding to the duplication - ensuring that no family faces 22q related challenges alone.

During this time, in partnership with our international family organization collaborators, we have worked tirelessly to raise awareness, striving to make 22q a household word, including via events such as 22q at the Zoo – Worldwide Awareness Day.

Leaning on our internationally recognized expert medical advisors, we have provided invaluable resources for healthcare providers and caregivers alike through our state-of-the-art **22q.org** website. Likewise, we have supported scientific and family educational programming, given we are committed to keeping the 22q community informed about current research developments and clinical advances - all while fostering vital interpersonal connections.

As we celebrate this 22-year journey, we reflect on the progress we've made and the impact we've had on countless families, scientists, and healthcare providers. It has sure been hard work, but more than worth the enormous effort. We thank every single volunteer who has helped us along the way and those who have trusted us to be the "go to" place for everything 22q. Together, we will continue our mission – to improve the quality of life for individuals affected by 22q differences through family and professional partnerships. Here's to many more years of making a difference!

Walking Down The Memory Lane

Back in 2003, a diagnosis of 22q11.2 deletion syndrome was not well understood, and many parents struggled for information about their child's treatment, care, and long-term outcomes. Many of them shared a common bond: isolation and uncertainty.

That year, a small group of parents and a local professional decided they wanted to make a difference. While sitting around a kitchen table in suburban Philadelphia, the group brainstormed about how they might help those affected by 22q11.2DS. Shortly thereafter the group created **The International 22q11.2 Deletion Syndrome Foundation, Inc.** with these goals:

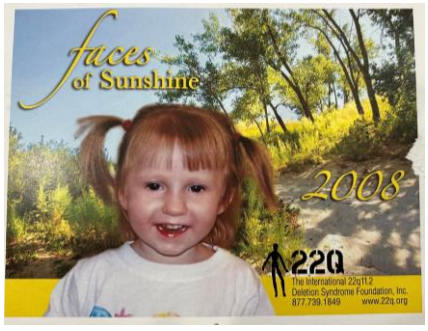
1. Improve detection;
2. Care for families;
3. Help raise awareness among clinicians, teachers, and the general public; and
4. Support research that would improve outcomes for affected individuals and their families.

2003 Founding board members

- Mark Abissi (Chair)
- Dottie Specht (Vice-Chair)
- Missy Disibio (Secretary)
- Wendy Rose (Treasurer)
- Donna McDonald-McGinn
- Mark Weinberg
- Carol Cavana

The foundation's first logo

22Q
The International 22q11.2
Deletion Syndrome Foundation, Inc.



In 2006, our Foundation unveiled the first **calendar fundraiser** with a 2007 calendar that showcased our loved ones. This tradition would continue for years to come. Here are the cover pages of the 2007 and 2008 calendars.

In 2008, our Foundation sponsored a booth at the American Society of Human Genetics (ASHG) conference in November in Philadelphia, PA, USA with a grant of $4,000

In 2011, our Foundation contributed significant financial support to the Dragonfly Forest Camp to help provide a wonderful week of overnight summer camp dedicated exclusively to campers with 22q.

The organizing committee of the very first **22q at the Zoo** posing in Philadelphia Zoo on May 22, 2011. Donna McDonald-McGinn was the person who coined the event name "22q at the Zoo – Worldwide Awareness Day". See the history of the event here.

Walking Down The Memory Lane (p. 2 of 4)

GRAND ROUNDS www.jpeds.com • THE JOURNAL OF PEDIATRICS

Practical Guidelines for Managing Patients with 22q11.2 Deletion Syndrome

Anne S. Bassett, MD,* Donna M. McDonald-McGinn, MS, CGC,* Koen Devriendt, MD, Maria Cristina Digilio, MD, Paula Goldenberg, MD, MSW, Alex Habel, MD, Bruno Marino, MD, Solveig Óskarsdóttir, MD, PhD, Nicole Philip, MD, Kathleen Sullivan, MD, PhD, Ann Swillen, PhD, Jacob Vorstman, MD, PhD, and The International 22q11.2 Deletion Syndrome Consortium**

In 2011, medical specialists from multiple countries published the **first set of clinical practice guidelines** for the care of individuals affected by 22q11.2 deletion syndrome. This document would help other medical professionals who are less familiar with this genetic syndrome.

In 2012 our new name was launched: **The International 22q11.2 Foundation, Inc.** Our team decided to drop the words "Deletion Syndrome" from the name as we expanded our services to include all individuals and families affected by abnormalities of chromosome 22q11.2. This included those with smaller deletions, those with changes in genes within the region such as TBX1, and those with 22q11.2 duplication syndrome. This was our logo after the name change:

22Q The International 22q11.2 Foundation, Inc.

This is the "Call for Abstracts" poster for the 2012 **Biennial International 22q11.2 Conference** in Florida. Our Foundation was proud to be the lead sponsor and convening organization for the family portion of this conference.

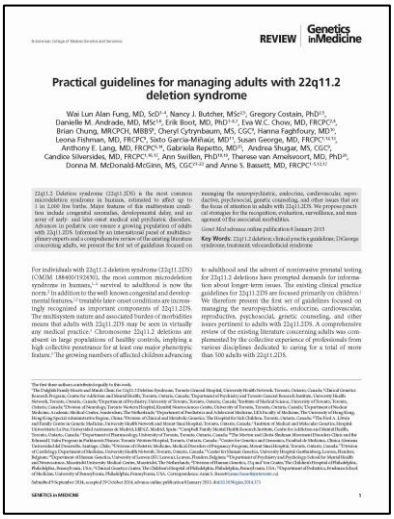
Since 1998, medical professionals and researchers, including many of our **Medical Advisory Board** members, have been getting together every 2 years to share their discoveries and experiences. The family meeting portion is a great opportunity for families to find out about the latest research and to support one another.

On January 26, 2012, multiple groups that represent families affected by 22q11.2DS rallied support for newborn screening for 22q11.2 before the US Secretary of Health's Committee on Heritable Disorders and Newborn Screening.

Back Row (Left to Right): Michelle Breedlove-Sells, The Ryan and Jenny Dempster Foundation; Carol Cavana, The International 22q11.2 Foundation; Anne Bassett, MD, The University of Toronto; Sheila Kambin, MD, The International 22q11.2 Foundation; Aoy Mitchell, PhD, Children's Hospital of Wisconsin.

Front Row (Left to Right): John Routes, MD, Children's Hospital of Wisconsin; Donna McDonald-McGinn, MS,CGC, Children's Hospital of Philadelphia; Julie Wootton, UK Max Appeal. Also present but not pictured was Stu Berger, MD, Children's Hospital of Wisconsin.

Walking Down The Memory Lane (p. 3 of 4)



REVIEW | Genetics in Medicine

Practical guidelines for managing adults with 22q11.2 deletion syndrome

Wai Lun Alan Fung, MD, ScD[1,2], Nancy J. Butcher, MSc[3], Gregory Costain, PhD[3], Danielle M. Andrade, MD, MSc[4], Erik Booth, MD, PhD[1,5], Eva W.C. Chow, MD, FRCPC[1,6], Brian Chung, MRCPCH, MBBS[7], Cheryl Cytrynbaum, MS, CGC[1], Hanna Faghfoury, MD[8], Leona Fishman, MD, FRCPC[9], Sixto Garcia-Miñaur, MD[11], Susan George, MD, FRCPC[1,10,12], Anthony E. Lang, MD, FRCPC[1,6], Gabriella Repetto, MD[13], Andrea Shugar, MS, CGC[1], Candice Silversides, MD, FRCPC[1,6,12], Ann Swillen, PhD[14,15], Therese van Amelsvoort, MD, PhD[16], Donna M. McDonald-McGinn, MS, CGC[17,18] and Anne S. Bassett, MD, FRCPC[1,3,5,12]

22q11.2 Deletion syndrome (22q11.2DS) is the most common microdeletion syndrome in humans, estimated to affect up to 1 in 2,000 live births. Many features of this multisystem condition include congenital anomalies, developmental delay, and an array of early- and late-onset medical and psychiatric disorders. Advances in pediatric care ensure a growing population of adults with 22q11.2DS. Informed by an international panel of multidisciplinary experts and a comprehensive review of the existing literature concerning adults, we present the first set of guidelines focused on managing the neuropsychiatric, endocrine, cardiovascular, reproductive, psychosocial, genetic counseling, and other issues that are the focus of attention in adults with 22q11.2DS. We propose practical strategies for the recognition, evaluation, surveillance, and management of the associated morbidities.

Genet Med advance online publication 8 January 2015

Key Words: 22q11.2 deletion; clinical practice guidelines; DiGeorge syndrome; treatment; velocardiofacial syndrome

For individuals with 22q11.2 deletion syndrome (22q11.2DS) (OMIM 188400/192430), the most common microdeletion syndrome in humans,[1,2] survival to adulthood is now the norm.[3] In addition to the well-known congenital and developmental features,[1,2] treatable later-onset conditions are increasingly recognized as important components of 22q11.2DS. The multisystem nature and associated burden of morbidities means that adults with 22q11.2DS may be seen in virtually any medical practice.[1] Chromosome 22q11.2 deletions are absent in large populations of healthy controls, implying a high collective penetrance for at least one major phenotypic feature.[4] The growing numbers of affected children advancing to adulthood and the advent of noninvasive prenatal testing for 22q11.2 deletions have prompted demands for information about longer-term issues. The existing clinical practice guidelines for 22q11.2DS are focused primarily on children.[1] We therefore present the first set of guidelines focused on managing the neuropsychiatric, endocrine, cardiovascular, reproductive, psychosocial, genetic counseling, and other issues pertinent to adults with 22q11.2DS. A comprehensive review of the existing literature concerning adults was complemented by the collective experience of professionals from various disciplines dedicated to caring for a total of more than 500 adults with 22q11.2DS.

In 2015, experts published the **first set of clinical guidelines specifically for the care of adults** affected by 22q11.2 deletion syndrome. This document would help other medical professionals who are less familiar with this genetic syndrome.

In 2016, we created and produced an educational and inspirational video for newly diagnosed 22q families. This video has been shared through social media and has been watched by thousands of expectant parents throughout the world. Click **here** to watch.

Runners, walkers, swimmers, and bike riders and volunteers raised awareness for 22q differences by participating in the 2016 Philadelphia and Denver USA Rock 'n Roll Half Marathon (22k) and Family Fun Run (5k or 10k) series.

In 2018, we incorporated our motto of **"Detection – Care – Cure"** into our logo:

The International 22q11.2 Foundation Inc.
www.22q.org

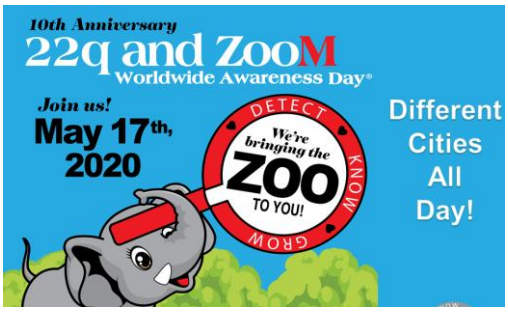
In 2021, we revamped our website and got a new logo. In this logo (which we are still using), the **heart** symbolizes the compassion and love we bring to our mission every single day, while our "**q chromosome**" highlights our unparalleled relationship with world experts who tirelessly volunteer on our Executive and Medical Advisory Boards.

22q International 22q11.2 Foundation

Fashion Show in the 22q Family Meeting in Sirmione, Italy, July 2016. Patients, family members, and researchers in the 22q community presented clothes designed by Tessa Koller.

Devin Booker and his family, as well as the Suns organization, hosted the International 22q Foundation "**Meet and Greet**" at the Phoenix Suns game in March 2020.

Walking Down The Memory Lane (p. 4 of 4)

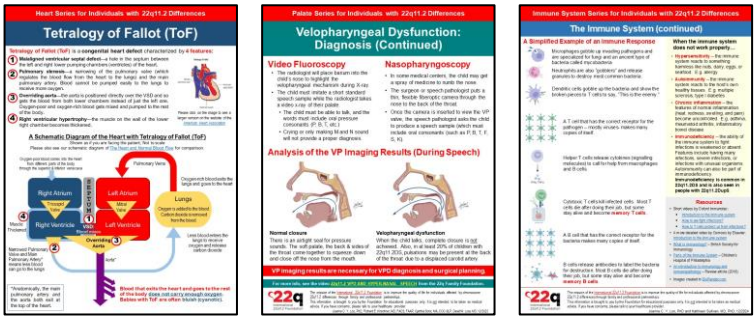


Because of the COVID-19 pandemic, 22q at the Zoo became **22q and ZooM**! We had a live virtual feed that went around the world for 24 hours in May 2020. Here is Donna McDonald-McGinn in the Zoom Meeting. Check out this **video** for more photos.

The CN Tower in Toronto, Canada was lit up in red to raise awareness for 22q differences on November 22, 2021. The "Luces por el 22q/Lighting the 22q" international movement began in Spain in 2018. Our Foundation promotes this event by providing templates for lighting request letters and showcasing photos of buildings in red.

The **Biennial Conference** resumed after the pandemic in 2022 in Split, Croatia. This is a group photo from the family meeting.

In 2021, we launched a new format for our **quarterly newsletter**. Each edition features research and medical information on 22q11.2 differences, as well as the latest news and events. **Sign up** to receive our newsletters!



To help families understand their conditions and navigate through medical appointments, we launched the **Health Conditions Explained** section on our website in 2022. As of February 2025, we have published the Palate Series, the Heart Series, the Dental Series, the Gastrointestinal Series, the Mental Health Series, the Speech Series, the Immune System Series, and the Glossary.

In early 2023, the **22q11.2 Society**, whose leaders and members include many of our Executive and Medical Advisory Board Members, published the new **prenatal guidelines** and the updated **pediatric** and **adult healthcare guidelines**. These new documents would make a huge impact on clinical care for patients and families worldwide. As of February 2025, the pediatric and adult guidelines have been translated into Spanish, French, and Chinese.

A Little History on 22q11.2 Deletion Syndrome

Have you ever wondered how far we have come in discovering knowledge around 22q11.2 deletion syndrome and building our support community?

Recently, the *Journal of Medical Genetics (JMG)* published the Six at Sixty series to reflect on key achievements and highlight some of the most influential research in the past 60 years. Professor **Peter Scambler**, from University College London in the UK, a founder and first chair of the **22q11.2 Society** and a member of our Foundation's **Medical Advisory Board**, was invited to write a **commentary on 22q11.2DS**. He wrote about the early years when his team (and a separate team involving our founding board member, Professor **Donna McDonald-McGinn** from the Children's Hospital of Philadelphia in the USA) published landmark studies on the clinical features associated with 22q11.2DS. Be sure to check out his commentary to find out more. You can also read about the start of the international conferences as well as the awareness and support initiatives.

Professor Peter Scambler

- **Six at Sixty. 'Have you tested for 22q?'** – Commentary (2025) by Peter Scambler; part of the Six at Sixty series and the February 2025 edition of JMG
- Spectrum of clinical features associated with interstitial chromosome 22q11 deletions: a European collaborative study – Research report (1997) by a team led by Peter Scambler
- The 22q11.2 Deletion: Screening, Diagnostic Workup, and Outcome of Results; Report on 181 Patients – Research report (1997) led by Donna McDonald-McGinn
- Same Name Campaign – Initiated by Donna McDonald-McGinn and our Foundation, also part of the website of the Dalglish Family 22q Clinic, Toronto, Canada; includes historical information on 22q11.2DS

Adult Congenital Heart Disease (ACHD): A Walk Down Memory Lane

Decades ago, before the 1960s, the vast majority of babies (with or without 22q differences) who were born with major congenital heart diseases (CHD) would not have survived. Over the years, heart surgeries for babies and children with CHD have become more and more successful. By the year 2000, over 90% of children with CHD survived to adulthood.

About 1 in 4 individuals with a 22q11.2 deletion (22q) is born with a major CHD. Although many are initially repaired during childhood, the heart needs to be checked by specialists throughout life. Staff members at the Dalglish Family 22q Clinic in Toronto, Canada, work closely with the experts at the Toronto ACHD (Adult CHD) program as they care for adults with 22q who have major CHD.

Recently, Dr. Jack Colman, a cardiologist who recently retired from the ACHD program, and his colleagues published a paper entitled Toronto ACHD program: A 65 year legacy. It describes the evolution of this trailblazing program at the Toronto General Hospital. The Program's journey began in 1959 with the early surgeries performed at the Hospital for Sick Children, then went through multiple stages over the years, all the while making pioneering advances to improve and extend the lives of adults with CHD.

The article notes many innovative aspects of this special program – including the Dalglish Family 22q Clinic led by **Dr. Anne Bassett**, the Medical Director of our Foundation. The Toronto ACHD group currently has over 12,000 active patients with all sorts of CHD conditions, and provides training and guidance to cardiologists and related specialist clinicians all over the world.

We invite you to take a trip down memory lane in Dr. Colman's article to see how far we have come on the care of ACHD. For information on CHD associated with 22q, please see the Heart Series in the **Health Conditions Explained** section of the website of our Foundation.

Toronto ACHD program: A 65 year legacy
Alonso-Gonzalez R., Benson L., Colman J.M., Harris L., Heggie J., Oechslin E., Silversides C.K., Williams W.G. International Journal of Cardiology Congenital Heart Disease, Volume 19, March 2025

22q Differences and Inflammatory Profiles

Differential inflammatory profiles in carriers of reciprocal 22q11.2 copy number variants.

O'Hora KP, Amir CM, Chiem E, Schleifer CH, Grigoryan V, Kushan-Wells L, Chiang JJ, Cole S, Irwin MR, Bearden CE.
Psychoneuroendocrinology. 2024 Nov;169:107135. doi: 10.1016/j.psyneuen.2024.107135. Epub 2024 Jul 20. PMID: 39116521.

Background Information

Inflammation is a normal part of our body's immune response to injuries and pathogens. The acute symptoms (pain, redness, swelling, and heat) help clear away the invaders and protect the host. However, inflammation can be harmful if it goes out of control, continues for too long, or attacks healthy tissues.

When immune cells need help battling pathogens, they release signaling molecules called **cytokines**. There are many different cytokines. The ones that promote inflammation include:

- Interleukin-6 (IL-6)
- Interleukin-8 (IL-8)
- Tumor Necrosis Factor α (TNF-α)
- Interferon-γ (IFN-γ)

These cytokines can go into the brain to activate the immune cells that protect the brain from infection and injury. However, immune activation and inflammation in the brain for a long time can lead to changes in mood, learning/thinking, and behavior.

Interleukin-8 (IL-8) is a cytokine that attracts other immune system cells to clear invading pathogens and protects the host. Higher levels of IL-8 have previously been associated with mental health conditions such as bipolar disorder, schizophrenia, and generalized anxiety disorder.

Psychosis is a symptom in which the person has difficulty telling apart what is real and what is not. They may hear voices or see things that are not there. They may believe that someone is out to harm them when this is not the case. Schizophrenia is a treatable **psychotic disorder** that is associated with **22q11.2DS**.

For more information on immunological and mental health conditions that are associated with **22q11.2DS** and **22q11.2DupS**, please check out our **Health Conditions Explained** webpage.

In this study, researchers checked to see if the blood sample levels of **cytokines involved in inflammation** are related to **mental health problems** and **sleep interruptions** in people with **22q11.2DS** and **22q11.2DupS**.

Study location/participants

- University of California at Los Angeles (UCLA)
- Participants (8 to 49 years) fit into 3 groups:
  - 45 with confirmed **22q11.2DS**
  - 29 with confirmed **22q11.2DupS**
  - 92 typically developed (TD) individuals with similar age and social characteristics as the test groups

Findings

- ↑ Body mass index was associated with ↑ levels of pro-inflammatory cytokines in all 3 groups of participants
- **22q11.2DupS** carriers had **higher IL-8 levels** compared to TD individuals, and to a lesser extent, **22q11.2DS** carriers
- There were no significant differences between the 3 groups in the levels of other pro-inflammatory cytokines.
- **22q11.2DS carriers with psychosis risk symptoms** had **higher IL-8 levels** compared to 22q11.2DS carriers with no psychosis risk symptoms.
- 22q11.2DS carriers with no psychosis risk symptoms had levels of IL-8 that were similar to those of TD individuals
- There were no significant relationships between sleep and pro-inflammatory cytokine levels.

Main message

- IL-8-related inflammatory activities may play a role in increased psychosis risk in individuals with **22q11.2DS**.
- ↑ IL-8 in **22q11.2DupS** carriers may indicate immune activities that are different from those resulting in ↑ IL-8 in **22q11.2DS** carriers. In other words, **22q11.2 deletions** and **duplications** may impact IL-8-related processes differently.
- More research is needed to understand the roles of IL-8 in 22q11.2 differences and in psychosis risk.

Immune System Series Now Available

In December, we presented 4 topics from the Immune System Series of the "**Health Conditions Explained**" section of our website. We have now generated info sheets for 4 more topics to complete the series. Special thanks to Dr. Kathleen Sullivan, Immunologist at the Children's Hospital of Philadelphia and Joanne Loo, Programmatic and Educational Tool Developer of our Foundation.

Published in December, 2024

- **The Immune System**
- **Vaccination**
- **Immune Deficiency Related to T Cells**
- **Immune Deficiency Related to B Cells**

Published in February, 2025

- **Autoimmune Disorders**
- **Allergies and Asthma**
- **Immune System Issues in 22q11.2DS**
- **Immune System Issues in 22q11.2DupS**

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

- **Heart Series**
- **Dental Series**
- **Palate Series**
- **Mental Health Series**
- **Speech Series**
- **22q Glossary (3rd ed.)**
- **Gastrointestinal (GI) Series**
- **Immune System 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 for 22q11.2DS Now Available in 4 Languages

A number of individuals as well as members of the 22q11.2 Society have been working hard on the translation of the clinical recommendation documents. Since we sent you our December newsletter, the French and Chinese translations of the pediatric clinical recommendations have become available. We thank Nicole Philip, Bekah Wang, Huiyun Wang, and Joanne Loo for their hard work and dedication.

The clinical recommendations for both children and adults are now available in 4 languages. The links to the original and all translations of the clinical recommendation documents will be posted on the 22q11.2 Society website as they become available.

Clinical Recommendations 2023

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

- **English** (Original)
- Spanish / Español
- French / Français **[NEW]**
- Simplified Chinese / 简体中文 **[NEW]**

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

- **English** (Original)
- Spanish / Español
- French / Français
- Traditional Chinese / 繁體中文

Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions

- English (Original)

19th Annual Faces of Sunshine Calendar


Cover

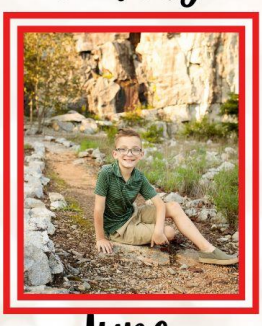

January


February


March


April


May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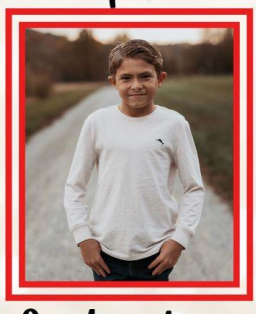
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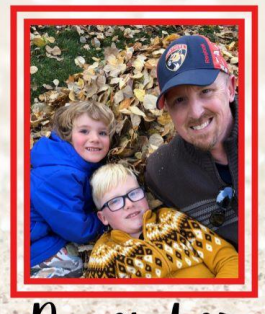
November


December

2025 FACES OF SUNSHINE

22nd q 2003-2025 Anniversary

22q International 22q11.2 Foundation

Many thanks to all who submitted photos for the 2025 calendar. The names of the featured individuals have now been posted on the **Calendar Campaign** webpage of the Foundation.

This calendar is a great way to show your 22q pride. We hope you enjoy the calendar as well as all of the beautiful faces of sunshine throughout 2025!

Calendars may be **ordered via our website**. All proceeds benefit the work of the International 22q11.2 Foundation, Inc.

Thank you for your support!

January – Gabriel E from Erwin, Tennessee
February – Penelope A from Bronx, New York
March – Sadie W from Binghamton, New York
April – Isabel S from West Fulton, New York
May – Hannah C from Sparta, Kentucky
June – Jaxson P from Hudson, North Carolina
July – Collins H from Brecksville, Ohio
August – Gavin R from Martinez, California
September – Landon V from Pylesville, Maryland
October – Gabriel "Gabe" D from Lexington, South Carolina
November – Cory, Collin & Trevor from Alberta, Canada
December – Sanibel A from Windsor, Colorado
…and the 2025 Cover Goes to:
Aideen U from Maple Shade, New Jersey

Did You Miss Our No Show Valentine's Ball?

It's not too late!

Instead of attending a ball in person, we invite you to make a donation to the International 22q11.2 Foundation. Your gift will support our work and help families with 22q differences.

Thank you!

Donate here

Donation Menu

• Table of 10 friends I do not have to persuade to attend!	$5222.00 USD
• Providing this gift in lieu of his & her new outfits!	$2222.00 USD
• Please accept this donation in place of raffle tickets!	$1222.00 USD
• It is not that I don't enjoy eating out!	$522.00 USD
• Saving on a Valentine's Day babysitter and Uber.	$222.00 USD
• Home before midnight – priceless!	$122.00 USD
• Cozy by the fire! – I'll take that any day of the week!	$52.00 USD
• Helping families in need!	$22.00 USD

2025 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 Saturday, November 22nd, 2025**. 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, 2025**, take pictures of yourself with the illuminated building and share them on social media.

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


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 cause 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 "Luces 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 it _____ 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

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/

22q International 22q11.2 Foundation

Lighting Request Letter

International 22q11.2 Foundation
15th Annual "22q at the Zoo®" Worldwide Awareness Day

22q at the Zoo
May 18th, 2025

22q at the Zoo is an annual event that happens at zoos and other fun places all around the world, giving families, friends and professionals a chance to socialize, network and raise public awareness of 22q11.2 differences.

In this event developed by the International 22q11.2 Foundation, volunteers spread awareness by handing out information about chromosome 22q differences. Participants are recognizable by wearing official **"22q at the Zoo" red T-shirts** and "**Ask Me About 22q**" buttons.

Visit our Foundation's **22q at the Zoo** webpage to check for an event in your area. The webpage will be updated on an ongoing basis as more volunteers step up to host the event.

If there are no 22q at the Zoo events in your area, you can host one! 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 at info@22q.org.

See you at the zoo on Sunday May 18th!

Upcoming Symposiums / Meetings / Gala

Florida Conquers 22q

March 29, 2025 (Saturday)
Joe DiMaggio Children's Hospital/ Memorial Regional Conference Center
Registration Link

The World View on 22q

Scientific symposium: Sept 4, 2025
Family Meeting: Sept 5-6, 2025
Philadelphia, Pennsylvania
More information to come.

Around the World with 22q

September 6, 2025
Philadelphia, Pennsylvania
More information to come.

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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