



International
22q11.2 Foundation

Newsletter March 2023

Greetings from the International 22q11.2 Foundation!

Can you believe that we are celebrating our Foundation's 20th anniversary? Check out pages 9 and 10 for our top accomplishments, and remember to join us on **Zoo Day** on **Sunday May 21st, 2023**.

We also have exciting news: **Three important documents for 22q11.2 deletion syndrome (22q11.2DS, or 22q) have just been published!** These include two sets of **updated clinical guidelines** for taking care of **children** and **adults**, respectively, and a **new** set for care during **pregnancies**. These guidelines will have a major impact, as they will help medical providers care for patients and families with 22q11.2DS worldwide. On pages 2 to 5 of this newsletter, we provide an overview and introduce you to each set of guidelines. Then on pages 6 to 8, you can read the inspirational story of Tammy, who was not diagnosed with 22q11.2DS until she was 42!

– The International 22q11.2 Foundation



22q at the Zoo Worldwide Awareness Day

Our annual 22q at the Zoo event aims to raise awareness about chromosome 22q11.2 differences while providing families, friends, and professionals a chance to socialize. The 2023 event will take place on **May 21st (Sunday)**. Please visit our **[22q at the Zoo](#)** page to find a participating zoo in your area. See you at the Zoo!



[History of the event](#) | [Photos \(06/2022 newsletter\)](#) | [Facebook page](#) | Inquiries: Info@22q.org

Now Available:

Updated Clinical Guidelines For 22q11.2DS

Since the publication of the first sets of guidelines for 22q11.2 deletion syndrome (22q11.2DS) in 2011 (for children) and 2015 (for adults), experts have learned a lot more about 22q11.2DS through clinical encounters and research. We are delighted to let you know that two sets of **updated clinical guidelines** for taking care of **children** and **adults**, respectively, as well as a **new** set for care during **pregnancies** have now been published! Please click on the links on the right to access them for free. **We encourage you to send a copy (or a link) of the relevant guidelines to your healthcare providers.**

We are enormously grateful for the [22q Society](#), which coordinated the massive effort of updating the guidelines. We would like to thank all those contributing to this work, in particular lead authors **Dr. Sólveig Óskarsdóttir**, **Dr. Erik Boot**, **Donna McDonald-McGinn**, **Dr. Anne Bassett**, and **Dr. Natalie Blagowidow**. In addition, **Lauren Lairson** provided immeasurable administrative support, and **Blaine Crowley** and **Joanne Loo** built and updated a database of medical literature that was crucial to the successful development of these guidelines.

We sincerely hope you are as excited about these milestones as we are, and we look forward to sharing our collective continued progress moving forward.

In the journal,
Genetics in Medicine

[Updated clinical practice recommendations for managing **children** with 22q11.2 deletion syndrome](#)

[Updated clinical practice recommendations for managing **adults** with 22q11.2 deletion syndrome](#)

In the journal,
Genes

[Prenatal screening and diagnostic considerations for 22q11.2 microdeletions](#)

Important: If you have any questions or concerns about your health, please discuss them with your healthcare providers.

Guidelines by the numbers

- Experts from 10 countries, covering >20 subspecialties, participated
- Patient advocacy groups from 7 countries, representing over 7000 families, gave input
- 2344 medical research articles about 22q11.2DS reviewed
 - 1545 about children and youth
 - 894 about adults
 - 100 about prenatal care (16 more were later added, yielding 116 in total)

Patient advocacy groups involved:

- [International 22q11.2 Foundation](#)
- [22q Foundation Australia & New Zealand](#)
- [22q11 Ireland](#)
- [Max Appeal, The United Kingdom](#)
- [Aidel 22, Italy](#)
- [Stichting Steun 22q11, The Netherlands](#)
- [22q11 Denmark](#)
- [22q11 Europe](#)

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

Sólveig Óskarsdóttir, Erik Boot, T. Blaine Crowley, Joanne C.Y. Loo, Jill M. Arganbright, Marco Armando, Adriane L. Baylis, Elemi J. Breetvelt, René M. Castelein, Madeline Chadehumbe, Christopher M. Cielo, Steven de Reuver, Stephan Eliez, Ania M. Fiksinski, Brian J. Forbes, Emily Gallagher, Sarah E. Hopkins, Oksana A. Jackson, Lorraine Levitz-Katz, Gunilla Klingberg, Michele P. Lambert, Bruno Marino, Maria R. Mascarenhas, Julie Moldenhauer, Edward M. Moss, Beata Anna Nowakowska, Ani Orchanian-Cheff, Carolina Putotto, Gabriela M. Repetto, Erica Schindewolf, Maude Schneider, Cynthia B. Solot, Kathleen E. Sullivan, Ann Swillen, Marta Unolt, Jason P. Van Batavia, Claudia Vingerhoets, Jacob Vorstman, Anne S. Bassett, Donna M. McDonald-McGinn.

Genet Med. 25(3): 100338, 2023. DOI: 10.1016/j.gim.2022.11.006.

This set of clinical practice guidelines focuses on the care of individuals from birth to 18 years of age. The emphasis is on **periodic assessments** and **family-centered care**.

Early diagnosis and treatment as well as **preventive management** are strongly recommended as they optimize health, functioning, and quality of life. Healthcare providers need to have basic knowledge about the variable, multi-system, and changing nature of 22q11.2DS. Specialists from various disciplines need to **provide coordinated care** and **tailor the treatment to suit the child**. Family members and caregivers are an essential part of the care team and benefit from information and support.

Figures and Tables at a Glance

- [Figure 1](#): A schematic diagram of the chromosome 22q11.2 region
- [Figure 2](#): Conditions (by specialty) that affect children and youth with 22q11.2DS and their risks
- Figure 3: [\(1\)](#) Organs and systems affected by 22q11.2DS and [\(2\)](#) the need for specialist care from infancy to adolescence
- [Table 1](#): **Recommendations for periodic assessments and management for children and youth with 22q11.2DS**
- [Table 2](#): Do's and Do not's when managing children with 22q11.2DS

General aspects covered

- Overview of management
- Genetics
- Genetic counselling
- Prenatal considerations

Areas covered

- Cardiovascular (heart)
- Palate/speech and language
- Obstructive sleep apnea
- Airway
- Ears/hearing
- Eyes/vision
- Dental abnormalities (teeth)
- Endocrinology (hormones)
- Growth
- Gastroenterology (digestion) and nutrition
- Genitourinary (reproductive health and generation of urine)
- General surgery
- Immunology (defense against infections; allergies)
- Hematology and oncology (blood, cancers)
- Musculoskeletal (muscles, bones, and joints)
- Neurology (brain and nerves) and neurosurgery
- Sleep
- Fatigue
- Mortality
- Cognitive functioning and development
- Psychiatry (mental health)
- Transition to adult care and internet safety

Click the link below to access the guidelines online for free!

[Updated clinical practice recommendations for managing children with 22q11.2 deletion syndrome](#)

Updated Clinical Practice Recommendations For Managing Adults with 22q11.2 Deletion Syndrome

Erik Boot, Sólveig Óskarsdóttir, Joanne C.Y. Loo, T. Blaine Crowley, Ani Orchanian-Cheff, Danielle M. Andrade, Jill M. Arganbright, René M. Castelein, Christine Cserti-Gazdewich, Steven de Reuver, Ania M. Fiksinski, Gunilla Klingberg, Anthony E. Lang, Maria R. Mascarenhas, Edward M. Moss, Beata Anna Nowakowska, Erwin Oechslin, Lisa Palmer, Gabriela M. Repetto, Nikolai Gil D. Reyes, Maude Schneider, Candice Silversides, Kathleen E. Sullivan, Ann Swillen, Therese A.M.J. van Amelsvoort, Jason P. Van Batavia, Claudia Vingerhoets, Donna M. McDonald-McGinn, and Anne S. Bassett. *Genet Med.* 25(3): 100344, 2023. DOI: 10.1016/j.gim.2022.11.012.

This set of clinical practice guidelines are developed for the care of individuals 18 years and older, covering life from the transition into adulthood all the way to the elderly age range. The emphasis is on **periodic assessments** to uncover and manage conditions that are later-onset or previously undetected.

Early diagnosis and treatment are important, and standard treatment strategies apply for each condition.. Healthcare providers from different specialties need to **provide coordinated care** and **tailor the management to suit the individual**, taking into account coexisting issues, intellectual disabilities, learning disabilities, mental health problems, and the changing nature of 22q11.2DS over time. In many cases, family members and caregivers continue to be an essential part of the care team.

Figures and Tables at a Glance

- [Figure 1](#): A schematic diagram of the chromosome 22q11.2 region
- [Figure 2](#): The estimated need for specialist care throughout the life span (from young adulthood onwards)
- [Figure 3](#): Conditions (by specialty) that affect adults with 22q11.2DS and their risks
- [Table 1](#): **Recommendations for periodic assessments and management for adults with 22q11.2DS**
- [Table 2](#): Do's and Do not's when managing adults with 22q11.2DS

General aspects covered

- Overview of management
- Genetic testing and related issues
- Genetic counselling
- Transition to adult care
- Aging and outcome
- Cognitive and adaptive functioning

Areas covered

- Psychiatry (mental health)
- Neurology (brain and nerves)
- Endocrinology and metabolism (hormones; reactions in the body)
- Cardiovascular and respiratory (heart- and lung-related)
- Sleep
- Gastroenterology (digestion)
- Genitourinary and gynecology (urine production; women's reproductive organs)
- Sexual and reproductive health, obstetrics (intimacy, pregnancy, childbirth)
- General surgery
- Skeletal (bones and joints)
- Immunology and related issues (defense against infections; allergies)
- Hematology and oncology (blood, cancers)
- Dermatology (skin)
- Sensory deficit (hearing, vision, smell)
- Dental (teeth)

Click the link below to access the guidelines online for free!

[Updated clinical practice recommendations for managing adults with 22q11.2 deletion syndrome](#)

Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions

Natalie Blagowidow, Beata Nowakowska, Erica Schindewolf, Francesca Romana Grati, Carolina Putotto, Jeroen Breckpot, Ann Swillen, Terrence Blaine Crowley, Joanne C. Y. Loo, Lauren A. Lairson, Sólveig Óskarsdóttir, Erik Boot, Sixto Garcia-Minaur, Maria Cristina Digilio, Bruno Marino, Beverly Coleman, Julie S. Moldenhauer, Anne S. Bassett and Donna M. McDonald-McGinn [ASB and DMM contributed equally to this work.]
Genes 14(1): 160, 2023. DOI: 10.3390/genes14010160

Many babies with conditions associated with 22q11.2DS require urgent medical attention at birth or soon afterwards. **Early diagnosis** can help provide the best after-birth care, which is especially important for newborns who have critical heart defects, but can also help those with more subtle health issues avoid a lengthy search for a definitive answer.

This article provides prenatal guidance for: (1) families with no history of 22q11.2DS; (2) prospective parents who have 22q11.2DS themselves; and (3) unaffected couples who already have a child with 22q11.2DS. There is discussion about **methods of obtaining samples** for prenatal genetic screening and testing, as well as physical features that may be seen on **imaging**. There is explanation about what each **testing method** can and cannot detect, and the importance of **genetic counselling**.

Topics covered

- Diagnostic testing in pregnancy
- Noninvasive prenatal screening (NIPS)
- Prenatal screening by ultrasound imaging
- First trimester ultrasound
- Third trimester ultrasound
- Prenatal screening by MRI imaging
- Reproductive options for a parent with 22q11.2 microdeletion

Subspecialty guidelines

22q11.2DS is a complex syndrome involving multiple body systems. Now that the 3 main guidelines are published, our experts plan to develop system-specific recommendations. This extensive work will take some time, but one set of subspecialty guidelines already exists. Please click the link below to access it for free:

[Speech-Language Disorders in 22q11.2 Deletion Syndrome: Best Practices for Diagnosis and Management](#)

Figures at a Glance

- [Figure 1](#): A schematic diagram on how 22q11.2 microdeletions happen
- [Figure 2](#): A schematic diagram of the chromosome 22q11.2 region
- [Figure 3](#): A flow diagram on how this set of clinical guidelines were developed
- [Figure 4](#): Proportion of fetuses with prenatal structural findings that turn out to have 22q11.2DS
- [Figure 5](#): Second and third-trimester ultrasound findings in 22q11.2DS

Tables at a Glance

(Access the full [guidelines](#) to see the Tables)

- Table 1: Features of 22q11.2 deletion that may be noticeable prenatally, at birth, or soon afterwards
- Table 2: A summary on studies that assessed non-invasive prenatal screen (NIPS) as a way to detect 22q11.2DS
- Table 3: Prenatal diagnostic findings
- **Table 4: Prenatal guidelines for 22q11.2DS**

Click the link below to access the guidelines online for free!

[Prenatal screening and diagnostic considerations for 22q11.2 microdeletions](#)

22q and me – Tammy’s Story

We are born with 23 chromosomes and inside these chromosomes there are thousands of genes. So, what does this mean for me?

DiGeorge syndrome affects the 22nd chromosome. The syndrome is now known as 22q11.2 deletion syndrome, or 22q. All I know is that missing this tiny piece of chromosome causes extreme havoc for me and other individuals with this syndrome. Who would have thought that missing such a tiny piece would cause such **HAVOC!** Not just the medical and physical aspects of it, but it also causes some disorders of the brain.

It took several frustrating years for me to be diagnosed as a 22q patient, 42 years to be exact. At least now I have the right team of specialists attending my care, and they understand 22q.

I am excited to know that the genetic testing can be done at birth: Fluorescent in situ hybridization (FISH) studies and other newer methods. It is very difficult to know what to look for because not all 22q patients have the same health issues or the same level of health issues. I have discovered that we do have a few symptoms in common to red flag the genetic testing for FISH; Heart defects, hypocalcemia, hypothyroidism.

So, from my personal perspective as a 22q patient this is what I have experienced. and continue to do so.

I was born with VSD: A ventricular septal defect (VSD) is a hole in the heart, 3 in fact. I did not have surgery. All I remember is that there were some tough times for my parents, and I was monitored closely for a few years, lots of visits to the hospital. As I got older the two holes somehow closed in. No surgery required. Just antibiotics before dental appointments. Dr. Lee said that I had one hole still open about the size of a dime. I wish I could speak with my Heart Specialist Dr. Lee from London, Ontario and let him know about the DiGeorge diagnosis (22q).



As I got older, I loved sports and joined the neighborhood swim team and baseball team. I wasn't as good as my siblings but enjoyed it. In swimming I occasionally came in third place and won an award for best sportsmanship in baseball, I even caught a few outfield balls and occasionally got on base.

At school, I was held back a year due to illness, so I attended the same grade as my younger sister. Not knowing I had 22q I was treated like everyone else in the class. I struggled with certain subjects like math and spelling. It took me years to figure out fractions. With hard work and determination, I graduated and received my grade 12 diploma. My favorite subjects were English, music and of course spare.

During high school I took the driver's education program, and it was a beneficial program. As for parallel parking it seems my peripheral vision played a role in me failing that part of the test. After lots of practice I did pass it the second time. I wasn't very good at parallel parking or comfortable with it so my friends knew if they were driving with me, if I couldn't find a spot to pull into, we had a lot of walking to do. No parallel parking. (To be continued on page 7)

Tammy's Story (continued)

I always dreamed of being a police officer and a writer. After graduating high school I moved to the big city of Toronto and took the Law and Security program. I was nervous and excited, moving from my parents' village home to the big city. First time away from home at the age of 18.

At that time, I still didn't know I was any different than any other college kid, sick a lot but that didn't stop me from socializing and enjoying college life. I enjoyed my courses, meeting new people and exploring the big city. Directions were not my strong suit; I will admit I got lost the first few times getting home from special events, ok more than a few. I have learned that landmarks are very important. At those times we didn't have google maps.

I was still dealing with a lot of unexplained medical issues, chronic infections, migraines, and hypocalcemia. My doctor at that time looked like Michael J. Fox. He was very supportive of me. I always seemed to have more than one medical issue to deal with. He dealt with the issues he could and referred me to different specialists to deal with the other medical concerns, not knowing about the missing genes.

After college I applied to a few police departments and failed the eye exam (Peripheral vision) and the physical so my dream as a police officer was crushed. I worked as a security officer for a while. I did have some exciting assignments that I can't name but also had some sleeper ones too. After a few years of working in security I decided to change careers and went back to school to get my Personal Support Worker Program diploma.

I worked in homecare and enjoyed working with seniors; it was my forte. My sister was posted to Kingston, so I moved in with her and was so excited about getting a job at a retirement home. They informed me that their

Personal Support Workers not only provided personal care for seniors, the PSW were responsible for administering medications, insulin and responding to emergencies

I really enjoyed working at the retirement residence. My coworker who I nicknamed "Jewels", did an awesome job training me. She was very patient. It took me several months to learn the medications. (It involved some fractions), finally I received my medication credits. One evening it was extremely busy, we were short staffed with a heavier workload. Unfortunately, this particular evening I ended up getting injured while lifting a resident. I dislocated my left clavicle, injured my neck and back. To this day I still suffer from chronic pain, numbness, and tingling to the left side and have a lump on my clavicle to remind me of the work injury.

It sure was a frustrating few years dealing with my work injury, I never dreamed that my work injury would be permanent. You think working double shifts, short staff, come in on your days off, your manager appreciates it. Maybe, maybe not...take care of yourself. When you get injured, they don't care, and throw you to the wolves. (At least my company did). I was determined and battled my insurance company. They requested to send me to their doctors.

The one doctor they sent me to see about my injury was a sweetheart. He totally believed me, and I do remember him saying, "It was going to affect me the rest of my life." Boy was he right.

I did try and work because I did not want to believe my injury was permanent. But failed because my injury interfered with everything I did; I was not reliable. I had to be under strict restrictions. One employer told me I had the qualifications, experience, and seniors enjoyed working with me, but because of the injury I was considered a liability. I left in tears and came to terms I was never going to work again. (To be continued on page 8)

Tammy's Story (continued)

I started having esophagus and throat issues. Other annoying symptoms that I didn't experience before my injury. Being yanked to the left side sure did lots of damage; enhanced 22q symptoms. My Kingston team of doctors wondered why I was not healing and decided to send me to the genetics specialist in Kingston. Six months later I was called into the specialist office for genetics and told I was born missing a piece of the 22nd chromosome. I was confused and cried, but also relieved. Finally, I had some answers. I was then sent to a team who specializes in 22q and they are located in Toronto, the Dalglish Family 22q Clinic. They truly have become my family. Very lucky to have them as my support team.

I am very appreciative of my family for their support, and I know when I was younger, I was a handful and will continue to be a handful... I also have great friends whom I don't have to name, have been supportive and continue to be while I have been going through this process, true lifers. Unfortunately, I am not working. I had to come up with some hobbies...I enjoy knitting, writing, photography and creating family videos. I also volunteer doing wellness checks for seniors, and advocate for personal support workers.

I continue to have a lot of hiccups along the way but that is just a brief synopsis.



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](#) (see below) and email your information to us at info@22q.org, along with two, high quality photos, and we will contact you for more information!

1. Tell us a little about yourself... where you were born? Your current age? What your childhood was like?
2. When were you first diagnosed with 22q deletion or duplication?
3. Tell us a little about school for you... any challenges posed by 22q? How did you overcome them?
4. What types of activities did you do growing up?
5. Tell us about your accomplishments.... Please share those you are MOST proud of... we would love to hear all about them!
6. Any advice you'd like to share to children growing up with 22q?
7. Goals for the future?
8. Did you go to college or secondary school? Tell us about that.
9. Anything else you'd like to share?

For more inspirational stories,
please visit:

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

Our Foundation's Top 20 Accomplishments

The International 22q11.2 Foundation celebrates 20 years of changing and improving the lives of individuals with 22q differences. We are committed to providing compassionate and innovative care, conducting research, and providing educational opportunities. In this section, let's take a look at our top 20 accomplishments. The Foundation has done a lot through the years, and it was not easy to select the top 20!

2023 – Our Executive and Medical Advisory Board Members published the new [prenatal guidelines](#) and the updated [pediatric](#) and [adult healthcare guidelines](#).

2022 – To help families understand their conditions and navigate through medical appointments, we launched the [Health Conditions Explained](#) section on our website in February. We have so far published the Palate Series, the Heart Series, the Dental Series, and the first edition of the 22q Glossary.

2018 – We created affiliate board member positions for our international collaborating organizations. We welcomed [Max Appeal](#) (United Kingdom), [22q Foundation Australia & New Zealand](#) (Australia), [22q Ireland](#) (Ireland), and [Aidel22](#) (Italy).

2016 – We created and produced an educational and inspirational video for newly diagnosed 22q families "[My Child has 22q](#)". This video has been shared through social media and has been watched by over eighty thousand expectant parents and families throughout the world.

2015 – Many members of the Medical Advisory Board were involved in the publication of the [Practical guidelines for managing adults with 22q11.2 deletion syndrome](#).

2015 – We published the **Family Support Network**, an extensive list of family support organizations around the world.

2014 – Our [Get Involved](#) webpage was created to guide families and professionals to help us reach our goals. Our 22q Programming includes providing support and resources for families, bringing newborn screening to a reality, as well as raising awareness.

2013 – In April 2013, Julie and Paul Wootton from Max Appeal arranged a **meeting at the British House of Commons**. Invited speakers, including our Board Member Donna McDonald-McGinn, MS, LCGC, gave Members of Parliament an overview of 22q.

2012 – Our new name was launched – We are now known as the **International 22q11.2 Foundation, Inc.** The words "Deletion Syndrome" were dropped from the name as we expanded our services to **include all individuals and families affected by abnormalities of chromosome 22q11.2**. This includes those with smaller deletions, those with changes in genes within the region such as **TBX1**, and those with the **22q11.2 duplication syndrome**.

2012 – In January, groups from the United States, Canada, and the United Kingdom had the opportunity to present before the US Secretary of Health's [Committee on Heritable Disorders and Newborn Screening](#) to rally support for newborn screening for 22q11.2. Participants from the Foundation included Donna McDonald-McGinn, MS, LCGC (Board Member), Dr. Anne Bassett, MD, FRCPC, (Chair of the Medical Advisory Board), Sheila Kambin, MD (Incoming Chair of the International 22q11.2 Foundation), and Carol Cavana (Parent and Outgoing Chair).

Our Foundation's Top 20 Accomplishments (continued)

2011 – Many members of the Medical Advisory Board were involved in the publication of the [Practical guidelines for managing patients with 22q11.2 deletion syndrome](#).

2011 – [22q at the Zoo – Worldwide Awareness Day®](#) launched for the first time on May 22, 2011. It was originally planned as a Philadelphia (USA) event but morphed into a worldwide phenomenon where people gathered at their closest zoo for a day of fun and solidarity while sporting our unique 22q at the Zoo T-shirts.

2010 – More than 800 **complimentary parent binders** were delivered to grateful individuals and to hospitals where they were distributed to 22q families. The binders helped families organize medical records, contact information and notes and included the educational booklet – **Birth to Five**.

2010 – In an effort to clear up the confusion over multiple names by which the deletion was known, we launched the [Same Name Campaign](#).

2009 – We launched the Foundation's [Facebook Group](#) and the [Newsletter](#).

2006 – The first [Calendar Fundraiser](#) was unveiled, beginning a tradition of showcasing our loved ones that would continue for years to come.

2005 – We broke ground as **granters**. The first grants were provided to families for travel to specialty camps. Soon, we would also provide grants for medical research.

2005 – The [Medical Advisory Board](#) was created. It which is comprised of specialists representing a broad spectrum of medical and science disciplines related to the 22q11.2 syndromes.

2004 – Board members worked very hard launching our [website](#), direct phone line, brochures, and logo to bring awareness to 22q11.2. Board members spoke at conferences and listened to parents and families to bring our vision and mission forward.

2003 – Mark Abissi extended an invitation to interested parties to attend a meeting to develop ideas for our **new non-profit group**. A name and a mission were created at our organization's family picnic and the 501 (c) 3 status is granted. Founding [Board Members](#) Mark Abissi (Chair), Dottie Specht (Vice-Chair), Missy Disibio (Secretary), Wendy Rose (Treasurer), Donna McDonald-McGinn, Marc Weinberg, and Carol Cavana worked together to launch **The International 22q11.2 Deletion Syndrome Foundation, Inc.**



A big **THANK YOU** to everyone who supported us and contributed to our cause.

Now let's celebrate together throughout 2023!

Donate Now

Our Goal: 2.2 Million Dollars

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!

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.

Copyright © 2022 - The International 22q11.2 Foundation, Inc.

International 22q11.2 Foundation, Inc.

PO Box 532, Matawan, NJ 07747

www.22q.org (877) 739-1849 **info@22q.org**