



A Healthy You and 22q

September 21, 2024



**NATIONWIDE
CHILDREN'S**

When your child needs a hospital, everything matters.®

A Healthy You and 22q

Program Description:

This program is intended to educate parents, caregivers and patients affected by 22q11.2 deletion syndrome. An opportunity to participate in live “chat rooms” with national experts will allow for roundtable discussion. There will be separate sessions for teens and school age children. Light refreshments and lunch will be provided.

Program Date:

September 21, 2024 | 8 a.m. to 4:30 p.m.

Location:

Nationwide Children’s Hospital Education Center
700 Children’s Drive | Columbus, OH 43205

Who Should Attend?

Parents, guardians, family members, caregivers of children with 22q, children with 22q and their siblings. Children must be accompanied by their parent or guardian.

Cost:

\$35 each adult

\$75 health care professionals

Teens and children are free



Confirmation:

A confirmation email with directions will be sent to all participants.

Conference Parking:

Parking is located in the Orange Parking Garage, located at 555 S. 18th St., Columbus, OH. Parking is \$2 for the day.

Questions:

For registration questions, call (614) 355-0662 or email CommunityEducation@NationwideChildrens.org.

Hotels:**The Drury Plaza Hotel**

88 E. Nationwide Blvd ,Columbus, OH 43215.

\$115 per night plus tax and parking based on availability.

Use corporate code 301765 when booking your room for this special rate.

Call 1-800-druryinn or log onto druryhotels.com.



About Columbus

Columbus is Ohio's capital and the nation's 14th largest city, with a dynamic business climate, a commitment to diversity, exciting annual festivals and cultural events, unique arts and entertainment opportunities and great professional, amateur and college sports. Columbus is located at the intersection of Interstate 70 and 71, within a one-day drive or a one hour's flight of 60 percent of the population of the United States and Canada.

Featured attractions for families include: Columbus Zoo and Aquarium, voted the favorite zoo of America by USA Travel guide. The zoo also operates an adjacent water park, Zoombezi Bay. Visit www.columbuszoo.org for more information.

COSI, featuring more than 300 interactive exhibits, has been ranked the No. 1 science museum for families by *Parents Magazine*. Visit www.COSI.org for information.

Family Dinner

Friday, September 20

If you're in town Friday evening, please plan to join other 22q families for dinner at The Old Spaghetti Warehouse, 150 S. High St., Columbus, OH 43215. Dinner starts at 5:30 p.m. and lasts until 8 p.m. You will get a separate email to reserve your spot after you register or you can call (614) 355-0662.

Dinner is for conference attendees only.



22q Walk and Family Brunch

Sunday, September 22, 9-11 a.m.

Whetstone Park of Roses Shelterhouse

3901 N. High St, Columbus, OH 43214

If attending the walk, please wear a red T-shirt. 22q Awareness T-shirts will be available for purchase at the conference and the brunch. Adult and children's sizes will be available. Food will be provided for all families that pre-register.

The park is 5-6 miles from Nationwide Children's Hospital.

If you have questions, contact

CommunityEducation@NationwideChildrens.org



Keynote Speaker

Gracie Chavez

Gracie was diagnosed with 22q deletion syndrome at the age of 2 and spent many years without resources or knowing anyone else with her condition. She educated herself about 22q and connected with others in the community. It was then she realized her passion to help and share awareness. She loves time with her family, blogging (she has a blog on the 22q Family Foundation site) and floral design. Gracie is the youngest of 5 children and the only one with 22q.



Agenda

Saturday, September 21

7:30 a.m. **Continental Breakfast and Check In**

8 a.m. **Welcome**
Adriane Baylis, PHD, CCC-SLP

8:15 a.m. **Keynote: Growing with Gracie- This is My Journey and I Love It!**
Gracie Chavez as interviewed by Adriane Baylis, PhD, CCC-SLP

8:45 a.m. **The New 22q Guidelines Panel**
Moderator: Adriane Baylis, PHD, CCC-SLP
Panel: Scott Hickey, MD, Peter Mustillo, MD

9:30 a.m. **Break**

9:45 a.m. **Medical and Developmental Panel**
Moderator: Richard Kirschner, MD
- Pulmonary – Kavitha Kotha, MD
- Gastroenterology – Karla Vaz, MD
- Sleep – Alpa Patel, MD

10:45 a.m. **Transitioning to Adult Care Panel**
Chaitali Amin, FNP
Amanda Smith, BSN, RN, CPN
Andrea Thompson, MSW, LISW

11:15 a.m. **Teen/Young Adult Panel**

11:45 a.m. **Family Lunch**

12:45 p.m. **Roundtable Briefing**

Roundtable Sessions

(You will choose one from the following pages in each time slot.
See registration form.)

Session I: 1-1:45 P.M.

- **Language, Speech and Velopharyngeal Dysfunction**
Adriane Baylis, PhD, CCC-SLP
Richard Kirschner, MD
It is common for children with 22q to have problems with communication skills and hypernasal speech. This workshop will discuss common concerns and treatment options including speech therapy and surgery.
- **Talking to the School About 22q**
Jennifer Cass, PhD
Ari Rabkin, PhD
Schools and parents both want children to succeed. During the workshop you will have the opportunity to get tips on best practices for success in working and communicating with your child's school system for the benefit of your child.
- **Picky Eaters**
Azure Koehler, FNP
Maleah Blake, MA, CCC-SLP
Our experts will answer questions about picky eating and, management approaches from infancy to the teen years.
- **Serious Mental Illness**
Richard Gilchrist, MD
Parents with 22q are often concerned about the current and future mental health of their child. Dr. Gilchrist will answer questions and help parents know what to look for and expect.

Session II: 2-2:45 P.M.

- **Executive Function and Social Interactions**

Camille Wilson, PhD

Executive function skills allow us to learn, work and manage daily life. Trouble with executive functions can make it hard to focus, follow directions and handle emotions. Learn strategies to help support executive functioning and peer social interactions.

- **Anxiety and Attention Challenges in Young Children**

Katherine Steingass, MD

Learn practical tips from each other and our expert on what you can do as a parent to help your child manage their anxiety and attention challenges.

- **Transition**

Chaitali Amin, FNP

Katrina Johnson, MD

Andrea Thompson, MSW, LISW

Transition is a period of planning and learning to be in charge of your own health care. The team will discuss with parents what transition looks like and how to prepare your child.

- **Growth Hormone**

Kathryn Obrynba, MD

Growth problems are common in children with 22q. Learn about what to expect, and the use of hormone therapy. Be ready to ask questions and share experiences.



Session III: 3-3:45 P.M.

- **Talking with the School About 22q**

Jennifer Cass, PhD

Ari Rabkin, PhD

Schools and parents both want children to succeed.

During the workshop you will have the opportunity to get tips on best practices for success in working with and communicating with your child's school system for the benefit of your child.

- **Parent Support Room**, hosted by 22q parents

A place to spend time to connect and chat with other 22q parents.

- **Autism**

Cara Inglis, PhD

Some children with 22q also have autism. Come learn more about autism and chat about strategies and resources to help your child.

- **Early Speech Language Development and Intervention**

Caitlyn Cummings, MA, CCC-SLP

Heidi Wyse, MA, CCC-SLP

Working with children early is a key to success in speech and language development. Discuss concerns, strategies and what parents can do to help their child.

3:50 p.m. **22q Family Foundation**

Lindsey Garcia, Executive Director

4:00 p.m. **Closing Remarks and Video**

Richard Kirschner, MD



Teen Group: Teen (12-15) Agenda

- 7:45 a.m. **Ice Breaker**
- 8 a.m. **Art Project**
- 9 a.m. **Flying Horse Farms**
- 11 a.m. **Move to Stecker Auditorium**
- 11:15 a.m. **Teen Young Adult Panel (in Stecker)**
- 11:45 a.m. **Family Lunch**
- 1 p.m. **Fitness Fun with Coach Q**
Chris Quickert
- 3 p.m. **Free Choice: Art/UNO/Games**
- 3:50 p.m. **Evaluation**
- 4 p.m. **Closing (in Stecker)**
- 4:10 p.m. **Closing Video**

School Age Group: Kids (7-11) Agenda

- 7:45 a.m. **Ice Breaker**
- 8 a.m. **Group games**
- 9 a.m. **Flying Horse Farms**
- 11 a.m. **Art Project**
- 11:30 a.m. **Family Lunch**
- 1 p.m. **Fitness Fun with Coach Q**
Chris Quickert
- 3 p.m. **Free Play: Play/Games/UNO**
- 3:50 p.m. **Evaluation**
- 4 p.m. **Closing (Main auditorium)**
- 4:10 p.m. **Closing Video**

Child Care

Children in the Pre-K group will have structured activities but will also be allowed plenty of free play. Children must be age 3 or older.

Exhibitors

- 22q team at Nationwide Children's On Our Sleeves
- 22q T-shirt Sales A Kid Again
- 22q Family Foundation Magical Moments Foundation
- Flying Horse Farms

Speakers (In alphabetical order)

Chaitali Amin, FNP

Nurse Practitioner, Plastic and Reconstructive Surgery,
Nationwide Children's Hospital

Adriane Baylis, PhD, CCC-SLP

Co-director, 22q Center, and Director, Velopharyngeal Dysfunction Program,
Plastic and Reconstructive Surgery, Nationwide Children's Hospital

Maleah Blake, MA, CCC-SLP

Speech-Language Pathologist, Nationwide Children's Hospital

Jennifer, Cass, PhD

Clinical Director, Neuropsychology, Nationwide Children's Hospital

Caitlyn Cummings, MA, CCC-SLP

Speech-Language Pathologist, Nationwide Children's Hospital

Richard Gilcrist, MD

Child and adolescent psychiatrist, Nationwide Children's Hospital

Courtney Hayes

Parent of a child with 22q

Katrina Johnson, MD

Internal Medicine, The Ohio State University Wexner Medical Center

Cara Inglis, PsyD

Psychology Supervisor/Clinical Manager for
Adolescent Transition Program and Behavioral Health Education Program
at the Center for Autism Spectrum Disorder (CAS),
Nationwide Children's Hospital.

Richard E. Kirschner, MD

Co-director, 22q Center, and Chief, Reconstructive and Plastic Surgery,
Nationwide Children's Hospital

Azure Koehler, FNP

Nurse Practitioner, Plastic and Reconstructive Surgery,
Nationwide Children's Hospital

Peter Mustillo, MD

Physician, Section of Allergy and Immunology,
Nationwide Children's Hospital

Kathryn Obrynba, MD

Endocrinologist, Section of Endocrinology, Nationwide Children's Hospital

Christopher Quickert, MEd

Founder, Homeschool gym and fitness teacher for Columbus Recreation Center

Ari Rabkin, PhD

Pediatric Neuropsychologist, Nationwide Children's Hospital

Amanda Smith, BSN, RN

Team Coordinator, 22 Center, Cleft, Lip and Palate Center and
Center for Complex Craniofacial Disorders, Nationwide Children's Hospital

Katherine Steingass, MD

Developmental and Behavioral Pediatrician, Developmental-Behavioral Pediatrics,
Nationwide Children's Hospital

Andrea Thompson, MSW, LSW

Social Worker, Nationwide Children's Hospital

Camille Wilson, PhD

Pediatric Neuropsychologist, Nationwide Children's Hospital

Heidi Wyse, MA, CCC-SLP

Speech-Language Pathologist, Nationwide Children's Hospital

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Conference Planning Committee

- Adriane Baylis, PhD, CCC-SLP
- Chatali Amin, FPN
- Rachel Dies
- Courtney Hayes
- Richard Kirschner, MD
- Megan Montgomery
- Ari Rabkin, PhD
- Marcie Rehmar, MS
- Rob Shepherd
- Amanda Smith, BSN, RN, CPN
- Andrea Thompson, MSW, LISW
- Veronica Weber





A Healthy You and 22q

2024 REGISTRATION FORM

SESSIONS

Session I is for adults

Session II is for teens (12-15)

Session III is for school-age children (7-11)

Session IV is for child care

NAME _____

WORKSHOP SELECTIONS (each adult selects one workshop per time slot)

1-1:45 p.m.

- Speech, Language and VPD
- Talking with the School
- Serious Mental Illness
- Picky Eaters

2-2:45 p.m.

- Anxiety and Attention
- Transition
- Executive Function
- Growth Hormone

3-3:45 p.m.

- Talking with the School (repeated session)
- Autism
- Parent Support Room
- Early Speech

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- Parent Support Room
- Early Speech

	√ if has 22q	Session	Age (if under 18)
Name _____	_____	_____	_____
Name _____	_____	_____	_____
Name _____	_____	_____	_____

Address _____

City _____ State _____ Zip _____

County _____

Daytime phone (____) _____ Fax (____) _____

Email _____

School District _____

Participating in the **Friday Family Dinner**. # of Adults _____ # of Children _____

Participating in the **Sunday Awareness Walk**. # of Adults _____ # of Children _____

I have reviewed the content of the teen and school-age program and allow my child(ren) to attend. Note: children will be talking and learning about 22q.

Family photo consents. Photos will be taken at the conference and may be used on the website and in written materials. We will have the consent for you to sign at the conference. If you do not plan to sign consent, please check here.

Please mark if you need: (indicate who this is for)

Vegetarian lunch _____ Wheelchair seating _____ Sign language interpreter _____

Other special needs _____

Conference Fees: \$35 each adult \$75 health care professional Teens and children free

Payment: Cash Visa MasterCard American Express Discover Check

Credit Card # _____ Exp. Date _____

Name on Card _____

Billing Address _____

Amount Enclosed \$ _____ Checks should be made payable to Nationwide Children's Hospital.

Mail this form to: Community Education, Nationwide Children's Hospital
700 Children's Drive, Columbus, Ohio 43205

Or register online at: [NationwideChildrens.org/22q-conference](https://www.nationwidechildrens.org/22q-conference)

Scan Here to
Register





NATIONWIDE CHILDREN'S

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