



# A Healthy You and 22q

September 17, 2022



**NATIONWIDE  
CHILDREN'S**

*When your child needs a hospital, everything matters.®*

# A Healthy You and 22q

*This program has been made possible through donations made to the Nationwide Children's Hospital Foundation and the 22q Family Foundation*

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## 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. Some sessions and chat room discussions will be broadcast live on the internet and will be available for playback on demand at a later date. Separate session for teens and school age children. Light refreshments and lunch will be provided.

*Lunch and Donna Cutler-Landsman sponsored by the generosity of the 22q Family Foundation.*

## Program Date:

September 17, 2022 | 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**

## Live Webinar:

Select conference sessions will be broadcast via live webinar for families that cannot attend the conference but would like the opportunity to ask questions of the roundtable speakers. To view the webinar, log onto [NationwideChildrens.org/22q-conference](https://www.nationwidechildrens.org/22q-conference) and click on the live webinar link. The webinar will be broadcast

between 1:10-3:45 p.m. EST. Families will be able to post questions directly to the group by email.

## 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](mailto:CommunityEducation@NationwideChildrens.org).

## Hotels:

A block of rooms has been reserved at:

### Holiday Inn Downtown Capitol Square

175 E. Town St, Columbus, OH 43215

\$85 night plus tax. Free parking.

Book your room by August 17 to get this rate. Call (614) 221-3281.

### Home2 Suites by Hilton

412 East Main St., Columbus, OH 43215

\$139 per night plus tax. Free parking.

Book your room by August 22 to receive this rate.

Call (614) 569-7760 for reservations. Group name is 22q Conference.

## Book Sales:

Autographed copies of *Sharing Love Abundantly in Special Needs Families*, will be available for sale at the conference.

## About Columbus

Columbus is Ohio's capital and the nation's 14<sup>th</sup> 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](http://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](http://www.COSI.org) for information.



## Educational Consultation

### Friday, September 16

22q families who attend the conference can sign up for a free, 20-minute educational consultation with Donna Cutler-Landsman on Friday afternoon.

Slots are first-come, first served. The link to sign up will be sent in your confirmation letter after registering for the conference.

## Family Dinner

### Friday, September 16

If you're in town Friday evening, please plan to join other 22q families for dinner at Plank's Cafe and Pizzeria. Stop by anytime between 5:30-8 p.m. Register for this with online conference registration, when you mail in your registration or call (614) 355-0662. *Family dinner sponsored by the generosity of Dr. Richard Kirschner.*

## 22q Walk and Family Brunch

### Sunday, September 18, 9-11 a.m.

Scioto Audubon Park  
400 W. Whittier St., Columbus, OH 43215

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 2.2 miles from Nationwide Children's Hospital.

If you have questions, contact

**[CommunityEducation@NationwideChildrens.org](mailto:CommunityEducation@NationwideChildrens.org)**

## Keynote Speaker

### Jolene Philo, MEd

Jolene grew up in a caregiving family and raised a son with medical special needs. As a teacher, she created an inclusive classroom for children with disabilities for 25 years. She's authored several books for the special needs and disability community, including *Sharing Love Abundantly with Special Needs Families: The 5 Love Languages® for Parents Raising Children with Disabilities*.

Jolene and her husband live in a multigenerational family in Polk City with her daughter, son-in-law and their two young children.



## Agenda

### Saturday, September 17

- 7:30 a.m. **Continental Breakfast and Check In**
- 8 a.m. **Welcome**  
Adriane Baylis, PhD, CCC-SLP
- 8:15 a.m. **Keynote: The 5 Love Languages, Raising Children With Disabilities**  
Jolene Philo, MEd
- 9 a.m. **Panel: Supporting Family Wellness and Mental Health**  
Jolene Philo, MEd  
Canice Crerand, PhD  
Parent panelists
- 9:45 a.m. **Break**
- 10 a.m. **Medical Panel**  
Vidu Garg, MD, Cardiology  
Jan Klamar, MD, Orthopedics  
Peter Mustillo, MD Immunology  
Kathryn Obrynba, MD Endocrinology
- 11 a.m. **Panel: Positive Changes in an Uncertain World**  
Ari Rabkin, PhD  
Nicole Dempster, PhD  
Parent panelists
- 11:45 a.m. **Family Lunch, sponsored by the 22q Family Foundation**
- 1 p.m. **Roundtable Briefing**
- 1:10 p.m. **Roundtable Sessions**  
(You will choose one from the following pages in each time slot.  
See registration form.)

**Session I: 1:10-1:55 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.*
- **Connecting With the School: ABCs of IEPs, 504 Plans and More**  
Donna Cutler Landsman, MEd  
*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.*
- **Feeding Across the Lifespan**  
Azure Koehler, APN  
Maleah Blake, MA, CCC-SLP  
*Feeding and swallowing disorders in 22q can range from picky eating behaviors, to aspiration requiring tube-feeding. Our feeding experts will discuss all aspects of feeding concerns and management approaches, from infancy to adolescence.*
- **Young Adult Workshop: Self Advocacy**  
(especially for older teens and young adults)  
Ari Rabkin, PhD  
*Designed to allow older teens and young adults to problem solve how to advocate for themselves, transition to adult care and manage daily living. Open forum will allow for discussion of topics relevant to the workshop participants.*

**Session II: 2:05-2:50 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.*
- **Prenatal Testing and Reproductive Medicine**  
Scott Hickey, MD  
Ashley Ebersole, MD  
*Prenatal testing and reproductive medicine are areas of medicine that are ever advancing. Session will explore current tests and trends, future of this field and what it means for you and your child.*
- **Mental Health**  
Richard Gilchrist, MD  
Canice Crerand, PhD  
*Parents with 22q are often concerned about the current and future mental health of their child. Experts will answer questions and help parents know what to look for and expect.*
- **The Medically Complex Child: Trachs, Feeding Tubes and Non-Verbal Communication Supports**  
Katherine Steingass, MD  
Ann Marie Polovick, MS, CCC-SLP  
Chaitali Amin, APN  
*Some children with 22q have multiple medical complications that require more complex management approaches. This special session is designed to help parents navigate these challenges in the home, medical and school setting.*

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

- **Connecting With the School: ABCs of IEPs, 504 Plans and More**  
Donna Cutler Landsman, MEd  
*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.*
- **Well-Being: Taking Care of Me**  
Jolene Philo, MEd, Jennifer Cass, PhD  
*Being a parent is tough. Being a parent of a child with special needs is every more difficult and it isn't easy to put aside "me time." This workshop will give tips on quick, easy ways to balance the self-time you need with the needs of your family.*
- **Breathworx614: Wellness Workshop**  
Tiffany Berger, Certified Rebirthing Breathworker and Life Coach  
*Based on ancient eastern practice such as yoga and Tai Chi, Breathworks helps align the body, mind and spirit by creating a sense of ease in our body. Join us for an introductory session to learn breathing techniques to reduce stress and promote calm.*

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

4 p.m. **Closing Remarks and Video**  
Richard Kirschner, MD

### Teen Group: Teen (12-15) Agenda

- 7:45 a.m. **Ice Breaker**
- 8 a.m. **Bingo**
- 8:45 a.m. **My World is Changing**
- 9:30 a.m. **Video Gaming**
- 11:45 a.m. **Family Lunch**
- 1 p.m. **Magic Show**
- 1:45 p.m. **Breathworx614**
- 2:15 p.m. **Flying Horse Farms**
- 3:15 p.m. **Free Time**
- 3:50 p.m. **Evaluation**
- 4 p.m. **Closing in Main Auditorium and 22q Day Video**

### School Age Group: Kids (7-11) Agenda

- 7:45 a.m. **Ice Breaker**
- 8 a.m. **Sibshops™**
- 11:45 a.m. **Family Lunch**
- 1 p.m. **Magic Show**
- 1:45 p.m. **Flying Horse Farms**
- 2:30 p.m. **Art Activity**
- 3:15 p.m. **Story Time: *The Abilities in Me***
- 3:30 p.m. **Free Play**
- 4:00 p.m. **Closing in Main Auditorium and 22q Day 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	BreathWorx
22q T-shirt Sales	On Our Sleeves
22q Family Foundation	A Kid Again
Flying Horse Farms	Magical Moments Foundation

## Speakers (In order of presentation)

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### **Adriane Baylis, PhD, CCC-SLP**

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

### **Canice Crerand, PhD**

Psychologist, Center for Biobehavioral Health, Nationwide Children's Hospital

### **Vidu Garg, MD**

Director, Center for Cardiovascular Research, and cardiologist, The Heart Center, Nationwide Children's Hospital

### **Jan E. Klamar, MD**

Orthopedic surgeon, Department of Orthopedics, 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

### **Ari Rabkin, PhD**

Pediatric neuropsychologist, Center for Complex Craniofacial Disorders and the Cleft Lip and Palate Center, Nationwide Children's Hospital

### **Nicole Dempster, PhD**

Psychologist, Nationwide Children's Hospital

### **Richard E. Kirschner, MD**

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

### **Jennifer, Cass, PhD**

Clinical director, Neuropsychology, Nationwide Children's Hospital

### **Scott Hickey, MD**

Geneticist, Section of Molecular Genetics, Nationwide Children's Hospital

### **Ashley Ebersole, MD**

Physician, Section of Adolescent Medicine, Nationwide Children's Hospital

### **Azure Koehler, FNP**

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

### **Katherine Steingass, MD**

Developmental and behavioral pediatrician, Developmental-Behavioral Pediatrics, Nationwide Children's Hospital

### **AnneMarie Polovik, MS, CCC-SLP**

Speech-language pathologist, Nationwide Children's Hospital

### **Chaitali Amin, FNP**

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

### **Maleah Blake, MA, CCC-SLP**

Speech-Language Pathologist, Nationwide Children's Hospital

### **Camille Wilson, PhD**

Neuropsychologist, Nationwide Children's Hospital

### **Richard Gilcrist, MD**

Child and adolescent psychiatrist, Nationwide Children's Hospital

### **Lindsey Garcia**

Executive director, 22q Family Foundation, mother of a child with 22q

### **Donna Cutler-Landsman, MS**

Cutler-Landsman Consulting, LCC and Special Education Advocacy specializing in 22q.11 deletion syndrome

### **Tiffany Berger**

Rebirthing breathworker and life coach

### **Conference Planning Committee**

Adriane Baylis, PhD, CCC-SLP	Stephanie Householder
Chatali Amin, FPN	Richard Kirschner, MD
Rachel Dies	Marcie Rehmar
Nicole Coggins	Ellen Seif
Amanda Glover, MSW, LISW	Amanda Smith, BSN, RN, CPN
Shannon Hogan	Veronica Weber





# A Healthy You and 22q

## 2022 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)

##### 1:10-1:55 P.M.

- Hypernasal Speech, VPD, Speech Surgery
- Connecting With the School
- Feeding Across the Lifespan
- Young Adult Workshop

##### 2:05-2:50 P.M.

- Executive Function
- Prenatal Testing and Reproductive Medicine
- Mental Health
- Medically Complex Child

##### 3-3:45 P.M.

- Connecting With the School
- Well-Being: Taking Care of Me
- Parent Support Room
- Breathworx 614

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- Parent Support Room
- Breathworx 614

	√ 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](http://NationwideChildrens.org/22q-conference)





# NATIONWIDE CHILDREN'S

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Columbus, Ohio 43205

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