



A Healthy You and 22q Conference

September 21, 2019



**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

Program Description:

This program is intended to educate parents, caregivers and patients with 22q11.2 deletion syndrome. We will share and discuss everything from medical concerns to questions about career transitions. An opportunity to participate in live “chat rooms” with local and 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. Light refreshments and lunch will be provided.

Program Date:

September 21, 2019 | 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:

\$30 each adult

\$60 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** and click on the live webinar link. The webinar will be broadcast between 1:45-4:30 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**.

Hotels:

A block of rooms have been reserved at:

Drury Inn & Suites Columbus Convention Center

88 East Nationwide Blvd., Columbus, OH 43215

\$175 per night. Triple room \$185. Quad room \$195 plus tax.

Register by August 22 to receive this rate.

Registrations can be made online at www.druryhotels.com by entering the group number 2354111 or calling 1-800-325-0720 and referring to the group number.

Parking fee is \$15 per day.

Free wireless internet and hot breakfast included.

Home2 Suites by Hilton

412 East Main St., Columbus, OH 43215

\$129 per night plus tax and parking.

Register by August 31 to receive this rate.

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

Photo credit: Positive Exposure (front page)

About Columbus

Columbus is Ohio's capital and the nation's 15th 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. Email CommunityEducation@NationwideChildrens.org or check the 22q Facebook page for details.

22q Walk and Family Brunch

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

Whetstone Park of Roses

3901 North High St., Columbus, OH 43214

If attending the walk, 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 available. Food will be provided for all families that pre-register.

If you have questions, contact

CommunityEducation@NationwideChildrens.org



Photo credit: Positive Exposure

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. **Promoting Resiliency**
 Brandon Kozar, PhD
- 9 a.m. **Resiliency Panel**
 9:45 a.m. **Break**
- HOT TOPICS**
- 10 a.m. **22q Guidelines and the Impact of Team Care**
 Scott Hickey, MD, Courtney Hall, MS, CPN
- 10:30 a.m. **Behavior and Development in Young Children With 22q**
 Katherine Steingass, MD, Ari Rabkin, PhD
- 11 a.m. **Panel Q & A**
 Scott Hickey, MD, Courtney Hall, MS, CPN,
 Katherine Steingass, MD, Ari Rabkin, PhD
- 11:10 a.m. **Guardianship**
 Logan Philipps, JD
- 11:40 a.m. **Career and Vocational Planning for Teens and Adults With 22q**
 Jason Osborn
- 12:15 p.m. **Musical Stylings of Nathan Seif**
 12:25 p.m. **Family Lunch**
 1:15 p.m. **Roundtable Briefing**
 1:45 p.m. **Roundtable Sessions** (choose 3)
- **Hypernasal Speech and Velopharyngeal Dysfunction**
 Adriane Baylis, PhD, CCC-SLP, Richard Kirschner, MD
 - **Speech-Language Therapy and Nonverbal Supports for Communication**
 Adriane Baylis, PhD, CCC-SLP,
 AnneMarie Polovik, MS, CCC-SLP
 - **ABCs of IEPs and School Services**
 Canice Crerand, PhD, Ari Rabkin, PhD
 - **Growing Up: Career and Vocation Transitions**
 Jason Osborn
 - **22q Medical Panel**
 Courtney Hall, MS,CPN - moderator, Cardiology- Jessica Bowman, MD, Endocrinology - Kathryn Obrynba, MD, Immunology - Peter Mustillo, MD
 - **Caring for the Medically Complex Child**
 Rukshana Ahmed, MD, Stephanie Lawrence, MD,
 Courtney Hall, MS, CPN
 - **Transitioning Into the Adult Health Care System**
 Kristina Booth, FNP, Rebecca Furr, MSW, LISW,
 Courtney Hall, MS, CPN
 - **Self-Care and Resiliency**
 Rachel Hibbard, Emily Snow, MSW, LISW, Canice Crerand, PhD
 - **Parent Support Room**
- 4:30 p.m. **Closing Remarks and Video**
 Richard Kirschner, MD

Teen Group: Teen (12-15) Agenda

- 7:45 a.m. **Ice Breaker**
 8 a.m. **Aromatherapy**
 8:45 a.m. **Bingo**
 9:15 a.m. **My Future: Careers**
 Jason Osborn
- 10 a.m. **Special Olympics**
 Zack Cotton
- 10:30 a.m. **Magic Show**
 11:30 a.m. **Self Care**
 Canice Crerand, PhD
- 12:15 p.m. **Music of Nathan Seif**
 12:25 p.m. **Family Lunch**
 1:15 p.m. **Flying Horse Farms**
 2:15 p.m. **Free Time/Slime/UNO**
 3:15 p.m. **Snack/Dog Visit/Face Painting**
 4:15 p.m. **Evaluation**
 4:30 p.m. **Closing in Main Auditorium**

School Age Group: Kids (7-11) Agenda

- 7:45 a.m. **Ice Breaker**
 8 a.m. **Bingo**
 8:30 a.m. **Art Activity**
 9 a.m. **Special Olympics**
 Zack Cotton
- 9:45 a.m. **Aromatherapy**
 10:30 a.m. **Magic Show**
 11:30 a.m. **Free Play/Slime**
 12:15 p.m. **Music of Nathan Seif**
 12:25 p.m. **Family Lunch**
 1:15 p.m. **Music Activity**
 2:15 p.m. **Dog Visit and Face Painting**
 3 p.m. **Snack**
 3:30 p.m. **Flying Horse Farms**
 4:15 p.m. **Evaluation**
 4:30 p.m. **Closing in Main Auditorium**

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 and toilet trained.

Exhibitors

- 22q team at Nationwide Children's
- 22q T-shirt Sales
- 22q Family Foundation
- Flying Horse Farms
- Special Olympics
- On Our Sleeves

Speakers (In order of presentation)

Adriane Baylis, PhD, CCC-SLP

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

Brandon Kozar, PhD

Director, Leadership Coaching and Development, Nationwide Children's Hospital

Canice Crerand, PhD

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

Scott Hickey, MD

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

Courtney Hall, MS, CNP

Pediatric Nurse Practitioner, Plastic & Reconstructive Surgery, Nationwide Children's Hospital

Katherine Steingass, MD

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

Ari Rabkin, PhD

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

Logan Philipps, JD, Principal, Resch, Root, Philipps & Graham, LLC

An attorney with concentration on planning for families with special needs children, Logan taught elementary school before obtaining his law degree.

Jason Osborn

A member of the 22q Family Foundation Team, Jason is a volunteer Career Coach, leveraging his background in Human Resources and formal education, which includes a Masters degree in HR and a Professional in Human Resources (PHR).

Richard E. Kirschner, MD

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

AnneMarie Polovik, MS, CCC-SLP

Speech-Language Pathologist, Nationwide Children's Hospital

Peter Mustillo, MD

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

Jessica Bowman, MD

Pediatric Cardiologist, The Heart Center, Nationwide Children's Hospital

Kathryn Obrynba, MD

Endocrinologist, Section of Endocrinology, Nationwide Children's Hospital

Stephanie Lawrence, MD

Internal Medical and Pediatrics, The Ohio State University Medical Center Internal Medicine and Pediatrics at Grandview

Rukshana Ahmed, MD

Pediatrician, Complex Care Program, Nationwide Children's Hospital

Rebecca Furr, MSW, LISW

Clinical Social Worker, Rheumatology, Nationwide Children's Hospital

Kristina Booth, FNP

Advanced Practice Nurse, Center for Colorectal and Pelvic Reconstruction, Nationwide Children's Hospital

Rachel Hibbard

Wife, mother of a 22q child and author of the book, "Just Jen: Living With Invisible Differences"

Emily Snow, MSW, LISW

Clinical Social Worker, Plastic and Reconstructive Surgery, Nationwide Children's Hospital

Conference Planning Committee

Adriane Baylis, PhD, CCC-SLP	Alicia Loechler
Megan BeVier	Marcie Rehmar
Nicole Coggins	Ellen Seif
Holly Conley, RN, BSN	Rachael Skaggs
Yavawn Garcia	Amanda Smith, BSN, RN, CPN
Felicia Gerasco	Emily Snow, MSW, LISW
Courtney Hall, MS, CNP	Rachel Solze
Richard Kirschner, MD	Christina Stocker



Photo credit: Positive Exposure

A Healthy You and 22q

2019 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)

1:45-2:30 P.M.

- ☐ Hypernasal Speech, VPD, Speech Surgery
☐ School IEPs
☐ Career and Vocational Transitions
☐ Medical Panel

2:45-3:30 P.M.

- ☐ Speech-Language Therapy
☐ Career and Vocational Transitions
☐ School IEPs
☐ Medically Complex Child

3:45-4:30 P.M.

- ☐ Speech-Language Therapy
☐ Transitioning to Adult System
☐ Self Care
☐ Parent Support Room

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☐ Self Care
☐ Parent Support Room

√ 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 _____

☐ Add me to the 22q Center parent support group mailing list.

☐ I allow my family information (parent name, email, city, state) to be put in the conference packet.

CONFERENCE FEES: ☐ \$30 each adult ☐ \$60 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



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Nationwide Children's Hospital
700 Children's Drive
Columbus, Ohio 43205

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