

Beads & Bling

It's a



Thing!

JULY 6-10, 2022

4P-NATIONAL CONFERENCE

MOBILE, ALABAMA

**2018 National Conference
San Antonio, Texas**



COVID EVENT SAFETY AND RESPONSIBILITY

ALL Attendees are required to provide the following:

- (1) Proof of full COVID-19 Vaccination** OR
- (2) Negative COVID-19 Test*** within 3 days of conference arrival. We will not accept an at-home rapid antigen test. A PCR or antigen test must be administered by a health care provider or pharmacy and results provided to conference organizers.

In alliance with the City of Mobile and other cultural institutions in the area, we are STRONGLY encouraging attendees to wear masks while at the Conference. However, masks are not required at this time.

We strongly encourage all attendees who are eligible to receive the COVID-19 Booster to do so prior to the conference.

** Per current CDC guidelines, you are fully vaccinated two weeks after your second dose in a two-shot series of the Pfizer-BioNTech or Moderna vaccines, or two weeks after a single-dose J&J/Janssen vaccine

***A negative Covid-19 test will be required of individuals 6 months of age and older.

Please note: The 4p- Support Group reserves the right to modify this current policy.

CONFERENCE HIGHLIGHTS



July 6-10, 2022
Mobile, Alabama

Our National Conference, held every two years, brings families, research scientists, and clinicians together in one place, at one time, for a multi-track meeting. Families and caregivers attend workshops, network with others, and celebrate their special children.

Highlights of this year's conference

- Keynote Speaker Heather Lanier, Author of Raising a Rare Girl and mother to Fiona (4p-)
- Presentations by Drs. John Carey Co-Chair of the 4p- Scientific Advisory Board
- On-site Family Fun Day
- SibShop for siblings ages 7-12
- Parent to Parent Conversations
- Kids' pajamas and movie night
- Beads and Bling Gala Dinner/Dance
- Silent Auction
- Free on-site childcare and sibling activities
- Sibling outings to GulfQuest Maritime Museum and Exploreum Science Museum



CONFERENCE HOTEL

Renaissance Mobile Riverview Plaza Hotel



64 South Water Street
Mobile, Alabama 36602
(251) 438-4000

<https://www.marriott.com/hotels/travel/mobrv-renaissance-mobile-riverview-plaza-hotel/>

Rate

Choice of Standard Room (King or Double)
\$140.00* per night + taxes

*The 4p- Support Group rate is good for 3 days before and 3 days after the conference dates, based on hotel's availability. All rooms are based on 2 adults, not including adults with 4p-. Taxes and service charges not included. Inform the hotel directly of any special needs.

Check-In: 4:00 PM | **Check-Out:** 11:00 AM

Each guest room provides a refrigerator, coffee maker, hairdryer, iron, flat screen television, and complimentary WiFi.

Discounted self-parking at \$12.00.

HOTEL DETAILS

Renaissance Mobile Riverview Plaza Hotel provides a setting that blends style, comfort and convenience. With 15 modern event spaces and a location in downtown Mobile, Alabama, we are ideal for all types of travelers. Visit historic destinations such as the USS Alabama and easily access John A. Campbell U.S. Courthouse. Following an action-packed day of work or play, retire to elegant rooms and suites featuring unforgettable views and an array of amenities to help you achieve a successful stay. Kick back in luxury with our pillowtop beds and sink into our plush chairs as you connect to our complimentary Wi-Fi and watch a movie on a large flat-panel TV. When it's time to refuel, treat your taste buds to a mouthwatering meal at The Harbor Room. For a relaxing environment with signature cocktails, live music and outdoor seating, visit Fathoms Lounge.



MAKE A HOTEL RESERVATION

Make your individual hotel reservations directly through our direct link. Select 'attende'. No code is needed.

<https://www.marriott.com/events/start.mi?id=1625151945674&key=GRP>

For the 4p- Support Group rate, reserve by:
June 6, 2022, 5:00 pm CST.

Please note:

The hotel has reserved rooms at our special conference rate of \$140 per night (called a block of rooms). Once these blocks of rooms have been booked, there is no guarantee that the hotel will have rooms available due to the high tourist season. We strongly urge you to book your hotel room as timely as possible. The June 6th date only refers to how long our special conference rate will be available.

Air Transportation

Mobile Regional Airport (MOB)
14 miles from hotel

Pensacola International Airport (PNS)
57 miles from the hotel

Gulfport-Biloxi International Airport (GPT)
72 miles from the hotel

New Orleans International Airport (MSY)
2 hours, 23 minutes from the hotel.

Transportation to and from the conference site is the responsibility of the conference attendees. Helpful links for various transportation companies are below.

<https://www.mobileairportauthority.com/mra/transportation/#rentals>

Local Host Families

Rich and Lori Johnson
Lovingrich@gmail.com
850.791.2409

Regional Director

Nicole Walker
region2@4p-supportgroup.org

DOWNTOWN MOBILE AREA

? INFORMATION

FREE moda! ROUTE

moda! STOPS

Look for the moda! stop umbrellas.
For moda! Information, call (251) 344-6600.

Business Improvement District
Within this district, please call their hotline 327-SAFE for information, vehicle assistance or safety escort services.

PARKS/GREEN SPACES

P PARKING

HISTORIC DISTRICTS

- ⋯ Church Street East
- ⋯ DeTonti Square
- ⋯ Lower Dauphin
- ⋯ Oakleigh Garden
- ⋯ Old Dauphin Way

FOR HISTORIC DISTRICTS OUTSIDE OF DOWNTOWN, VISIT MOBILEHD.ORG/MAPS.HTML



DOWNTOWN ATTRACTIONS

- 1 [Renaissance Mobile Riverview Plaza Hotel](#)
- 2 [Mobile River Boat Cruises](#)
- 3 [USS Battleship Alabama](#)
- 4 [Mobile Carnival \(Mardi Gras\) Museum](#)
- 5 [Exploreum Science Center](#)
- 6 [GulfQuest National Maritime Museum](#)
- 7 [Cathedral of Immaculate Conception](#)
- 8 [History Museum of Mobile](#)
- 9 [Daughters of the Revolution \(DAR\) Museum](#)
- 10 [Fort Conde](#)

LOCAL ATTRACTIONS

- [Bragg-Mitchell Mansion](#) 3.5 miles from Hotel
- [Toomey's Mardi Gras Store](#) 4.5 miles from Hotel
- [Mobile Japanese Walking Garden](#) 11 miles from Hotel
- [Mobile Museum of Art](#) 12 miles from Hotel
- [Mobile Botanical Gardens](#) 12 miles from Hotel
- [Mobile Bay Ferry](#) 36 miles from Hotel
- [OWA Park & Recreation](#) 42 miles from Hotel
- [Alabama GulfCoast Zoo](#) 48 miles from Hotel)
- [Waterville USA](#) 52 miles from Hotel

Hospital

Children's & Women's Hospital | USA Health
2 miles from hotel

700 Center Street
Mobile, Alabama 36604
251.415.1000
usahealthsystem.com

Mobile Visitor Info

<https://www.mobile.org>



SCHEDULE

Wednesday, July 6, 2022

- 11:00a-5:00p Conference Check-in**
(2nd Floor Lobby and Jubilee Suite)
Packet pickup and conference updates
Personalized Family Photos
- 4:00p-5:30p First Time Attendee Session**
Intimate gathering to provide one-to-one introductions, overview of conference schedule and events, and introduction to the 4p- Support Group
- 6:00p-9:00p Welcome and Meet & Greet**
Introductions
Raffle
Light Dinner

Thursday, July 7, 2022

- 8:30a-5:30p Childcare/Sibling Activities**
Closed for lunch from 12:30a - 1:15p
- 9:30a-9:45a President's Welcome**
- 9:45a -11:00a Keynote Speaker**
Heather Lanier, Assistant Professor of Writing Arts at Rowan University and mother to Fiona (4p-)
- 10:00a-2:00p SibShop**
Ages 7-12
(Must be pre-registered)
- 10:00a-2:00p Sibling Outing**
Exploreum Science Museum
Ages 7+
(Must be pre-registered)
- 11:00a-11:15a Break**
- 11:15a-12:30p WHS: General Session - Latest Updates**
Dr. John C. Carey
- 12:30a-1:15p Childcare Closed for Lunch**
- 12:30a-1:30p Complimentary Boxed Lunch**
- 1:30p-2:30p Breakout Sessions (choose one)**
WHS: Overview of Basic Care Recommendations - Dr. Carey
Navigating IEP's
Endocrinology - Boys
Discussion Circle* - Selfcare for Parents/Guardians of 4p- Individuals

Thursday, July 7, 2022 (continued)

- 2:30p-2:50p Break**
- 2:50p-3:50p Breakout Sessions (choose one)**
WHS: Overview of 2021 Adult Study
Endocrinology - Girls
Trusts/Able accounts
Discussion Circle* - Selfcare for Parents/Guardians of 4p- individuals
- 3:50p-4:10p Break**
- 4:10p-5:10p Breakout Sessions (choose one)**
Genetics 101
Urology 101
Socialization/Friendships for Children & Adults with Special Needs
Feeding and Oral Issues
Discussion Circle* - Anticipatory Grief
- 5:30p Childcare Closes**
- 5:30p-7:00p Dinner on Your Own**
- 7:00p-9:00p Ice Cream Social**

Friday, July 8, 2022

- 8:30a-5:15p Childcare/Sibling Activities**
Closed for lunch from 12:30p-1:15p
- 10:00a-2:00p Sibling Outing**
GulfQuest National Maritime Museum - Age 7+
(Must be pre-registered)
- 9:00a-10:00a 4p- Support Group Family Meeting**
- 10:20a-11:20a Breakout Sessions (choose one)**
ABCs of CBD/The science and health benefits of Cannabidiol (session repeated at 11:40)
Neurology 101
ABA Therapy: Concepts of Reinforcement and Punishment
Guardianship, Legal Planning
Discussion Circle* - Marriage/Communication
- 11:20a-11:40a Break**
- 11:40a-12:40p Breakout Sessions (choose one)**
ABCs of CBD/The science and health benefits of Cannabidiol (repeated session)
Project SEARCH: Developing employability and life skills
ABA Therapy: Functions of Behavior
Discussion Circle* - Marriage/Communication

Friday, July 8, 2022 (continued)

- 12:40p-1:40p Lunch on Your Own**
- 12:40p - 2:40p Childcare Closed for Lunch**
- 1:40p - 2:40p Age Group Photos & Group Photo**
- 2:40p Childcare Reopens**
- 3:00p-5:00p Discussion Circles***
Moms
Dads
Grandparents/Extended Family
- 5:15p Childcare Closes**
- 5:30p-7:00p Dinner on your own**
- 7:00p-9:00p Parent to Parent Evening Social**
- 7:00p-9:00p Kids' Pajama & Movie Night**
Childcare Provided
Movies, Refreshments & Games

Saturday, July 9, 2022

- Breakfast on your own**
- 8:30a-9:30a Yoga**
- 9:30a-10:30a Introduction to CPR for children and adults with special needs**
(no certification provided)
- 11:00a - 5:00p Family Fun Day - On-site**
(Final schedule of Events to be provided at conference)
- 5:30p-6:30p Pre-Gala Events**
Photo Booth
Silent Auction begins - Bid on gift sets, handmade items, collectibles, and more with all the proceeds benefiting our support group!
- 6:30p-10:00p Beads and Bling...It's a 4p-Thing! Gala Dinner/Dance**
Semi-formal or formal attire is encouraged, but not required.
Dinner Buffet
Silent auction commences
Music and dancing

Sunday, July 10, 2022

- 9:00a-10:00a Conference Reflection & Fellowship**
- 12:00p Hotel Checkout**

**Denotes a Discussion Circle. Due to the nature of these sessions, they are reserved for 4p- parents only.*

Please note that this schedule is subject to change. Please check our website for the most current schedule: 4p-supportgroup.org

CONFERENCE PRESENTERS

2022 KEYNOTE SPEAKER



HEATHER LANIER

Assistant Professor of Writing Arts at Rowan University and mother to Fiona (4p-)

Heather Lanier illuminates truths about the human condition that speak to both the head and the heart.

Heather is a poet, essayist, teacher, speaker, and thrift-store shopper. An assistant professor of creative writing at Rowan University, she is the author of the memoir, *Raising a Rare Girl* (Penguin Press, July 2020), along with two award-winning poetry chapbooks, *The Story You Tell Yourself*, and *Heart-Shaped Bed in Hiroshima*. She is the recipient of a Vermont Creation Grant and an Ohio Arts Council Individual Excellence Award.

Her essays and poems have been published in *The Atlantic*, *The Sun*, *Salon*, *Brevity*, *Vela Magazine*, and elsewhere. Her TED talk, “‘Good’ and ‘Bad’ Are Incomplete Stories We Tell Ourselves,” has been viewed over two million times. With an MA in Teaching from Johns Hopkins and an MFA in Creative Writing from Ohio State, she has taught Shakespeare to ninth graders in Baltimore, conversational English to housewives, ship workers, and executives in Japan, and composition and creative writing to undergraduates at places such as UC Berkeley, Miami University, and Southern Vermont College.



John Carey, MD, MPH

Professor of Pediatrics
University of Utah School of Medicine
Salt Lake City, Utah

John C. Carey, MD, MPH, is Professor and formerly Vice Chair of Academic Affairs, Department of Pediatrics, at the University of Utah. Dr. Carey joined the faculty at University of Utah Health Sciences Center in 1979. He became Chief of the Division of Medical Genetics in 1985 and remained in that leadership position until 1999 when he stepped down to assume the role as Editor-in-Chief of the *American Journal of Medical Genetics*. He has held that editorial position from 2001-2016; he is now an Associate Editor of the *Journal*. Dr. Carey established the Medical Genetics Fellowship Program at the University of Utah and stepped down in 2014 and continues as a mentor in the Program. Dr. Carey’s research focus has been in congenital malformations, neurofibromatosis, and syndrome delineation. He has authored or co-authored over 300 papers, chapters, invited articles, and editorials for scientific journals. He co-authored the textbook, “*Medical Genetics*,” by Jorde, Carey, & Bamshad, now in its 6th edition. The book is a widely used text in schools of medicine throughout North America and Europe.

“It is the right and the need of each patient with WHS to receive not just the ordinary care given to any child but the extraordinary care necessary for coping with the problems of the del(4p) disorder.”

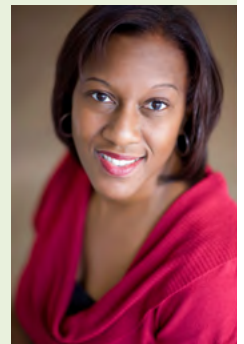
John C. Carey, MD

Dr. Carey is the Co-Medical Advisor of the 4p- Support Group and followed the oldest known living patient with the condition (who passed away at the age of 71 in 2021). As a clinical scientist and geneticist focusing on chromosome syndromes, Dr. Carey has had the opportunity of chairing and helping to organize the Research Workshops on Wolf-Hirschhorn syndrome (WHS) and the 4p- Related Disorders in 2008, 2012, 2014, 2015, 2016, 2017 and 2018 (sponsored by the 4p- Support Group), as well as the informal “meet and greets” between clinicians and families at the 2010 National Conference (Salt Lake City, UT). The proceedings and presentations of the 2008 meeting led to the issue in the *American Journal of Medical Genetics*, Part C devoted to WHS and the related disorders.

DISCUSSION CIRCLES

DR. MEKEL HARRIS

Mekel Harris, Ph.D., NCSP is a practicing psychologist based in Memphis, Tennessee. She completed her pre- and post-doctoral level training at Children’s Hospital Los Angeles, where she enhanced her clinical skills working with children diagnosed with an array of acute and chronic health conditions, as well as their families. Dr Harris has presented at over 25 national and international conferences addressing child and family health issues, palliative care and grief and loss. In 2016, Dr Harris attended the 4p- National Conference in Los Angeles where she facilitated a variety of discussion circles and met with over 90 4p- families. In 2021, Dr Harris was instrumental in creating the 4p- Support Group’s first “virtual” discussion group platform which continues to serve the 4p- community today.



**SATURDAY
FAMILY
FUN DAY**



Schedule

Final schedule of Events to be provided at conference



**Mardi
Gras
Parade**

Auction

Gala

**Arts &
Crafts**

**Dance
Party**

**Character
Appearances**

Lunch

**Door
Prizes**

**Drum
Circles**

CONFERENCE SPECIAL ACTIVITIES

CHILDCARE & SIBLING ACTIVITIES AT HOTEL

Childcare & sibling activities will be available for individuals with 4p- and their siblings. There is no charge for childcare and all ages are welcome.

Entertainment and Activities

- Arts and crafts
- Board games
- Music
- Movies
- Snacks
- Video games

Designated Childcare Areas

Including play rooms and teen/young adult lounge

Note: Complete schedule of childcare activities will be distributed at Conference Check In.



SIBSHOP WORKSHOP at Hotel

Thursday, July 7 - 10:00a - 2:00p

Ages 7-12

\$10 per child – includes lunch

Space limited | Must pre-register

Sibshops are celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs can bring challenges. They reflect a belief that brothers and sisters have much to offer one another - if they are given a chance. Sibshops are a spirited mix of new games (designed to be unique, off-beat, and appealing to a wide ability range), new friends, and discussion activities.

Sibling Outings*



Thursday, July 7, 2022 Exploreum Science Museum

10:00 a.m. - 2:00 p.m.

Sibling Age: 7 and up

Outing Fee: \$25 Includes admission and lunch

Must pre-register

[Gulf Coast Exploreum Science Center of Mobile, AL](https://www.exploreum.org/)



Friday, July 8, 2022 GulfQuest National Maritime Museum

10:00 a.m. - 2:00 p.m.

Sibling Age: 7 and up

Outing Fee: \$25 Includes admission and lunch

Must pre-register

[GulfQuest : National Maritime Museum](https://www.gulfquest.org/)

*We kindly request that no parents participate in either outings, so that siblings can have a day to share in fellowship with other siblings. Chaperones will be available at a ratio of 1:4 for those participants ages 7-11. Participants ages 12+ will have a chaperone at a ratio of 1:8.

*Masks may be required

GENERAL INFORMATION

2022 CONFERENCE REGISTRATION

| Registration Fees | Early Bird prior to April 15 | April 16 - June 6 |
|---|------------------------------|-------------------|
| Parent/Guardian | \$100 | \$125 |
| All other adults (18 & over)* | \$150 | \$175 |
| Children ages 11 - 17* | \$100 | \$125 |
| Children ages 2 - 10* | \$75 | \$100 |
| 4p- Individuals (any age) & Children under 2 | FREE | |
| Registration late fee per family if received after June 6 | | \$200 |

*Fees determined by age as of July 6

Cancellation policy: Registration fees are fully refundable until June 6, 2022. If you must cancel after June 6, all registration fees made will be donated to the 4p- Support Group's conference scholarship fund. This donation will qualify as a charitable donation. Late cancellation for refund due to an emergency will be considered on a case-by-case basis.

For information on our conference scholarship fund, go to:

4p-supportgroup.org/conference-scholarship

ON-LINE REGISTRATION HERE 4p-supportgroup.org/registration2022



DON'T FORGET TO ORDER YOUR CONFERENCE T-SHIRTS

Conference T-shirts bearing the conference logo are available only through pre-sale and will be ready for pick up at the conference check-in. See conference registration for details. Limited additional merchandise may be available for purchase during the conference. Cash and credit cards accepted (no checks).

*Photo for example purposes only.



2022 CONFERENCE CONTACTS

Susan Bear
(812) 204-5375
Susan@4p-supportgroup.org

Amanda Lortz
(614) 307-1092
amanda@4p-supportgroup.org



4P- SUPPORT GROUP

The 4p- Support Group is a non-profit association for families affected by 4p- and related 4th chromosomal conditions. We offer phone support, newsletters, national biannual gatherings and regional meetings to meet and exchange experiences and information. We welcome parents, foster parents, relatives, and professionals working with individuals with 4p- and their families. Our mission is to serve our membership by providing information, education and support; uniting families, researchers, and professionals; and promoting awareness and understanding of 4p- syndrome, with Wolf-Hirschhorn Syndrome as the main condition, and the related 4th chromosome abnormalities. For membership information please visit our website: www.4p-supportgroup.org/

You can help by donating items

SUPPORT OUR CONFERENCE SILENT AUCTION

We are seeking donations of new items to be auctioned off during our exciting Saturday evening Gala. Your generous donations are tax deductible and all proceeds will benefit the families of the 4p- Support Group.

Items we are looking for

- Gift Cards (preferably to national chains or online businesses)
- Tickets to Attractions or Movies
- Art & Handmade One-of-a-Kind Pieces
- Books or Toys
- Beauty, Spa or Therapeutic Items
- Wine & Gift Baskets
- 4p- Related Gifts

To donate an item, please contact:

Amanda Lortz
amanda@4p-supportgroup.org
(614) 307-1092

Thank you in advance for your support!



You can help by donating items from our Amazon Wish List!

[amazon.com/hz/wishlist/ls/38VEA1BT85VPB](https://www.amazon.com/hz/wishlist/ls/38VEA1BT85VPB)

MEMORIES

2018 CONFERENCE San Antonio, Texas 90+ Families



DEEP IN THE
HEART OF 4P-

