Deep in the Heart of 4p-

2018 National Conference
July 25-29 2018 ★ San Antonio, Texas
CONFERENCE HIGHLIGHTS

July 25-29, 2018
San Antonio, Texas

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 include:

• Keynote Speaker Major Kim “Rooster” Rossiter, US Marine Corps
• Presentations by Drs. John C. Carey and Amy R.U.L. Calhoun, Chairs of the 4p-Scientific Advisory Board
• Family Fun Day at Morgan’s Wonderland, world’s first accessible family fun park
• SibShop for siblings ages 7-12
• Resource Fair
• Parent to Parent Conversations
• Kids’ Pajama Party
• Diamonds and Denim-themed Gala Dinner/Dance
• Silent Auction
• Free on-site childcare and sibling activities
• Sibling outing to the San Antonio Zoo
Hotel Details

Set amidst a blend of histories and a modern city, the Grand Hyatt has a premier location on the San Antonio River Walk and is within walking distance of the Alamodome, Tower of The Americas, and the The Alamo. The location provides event goers access to iconic riverside restaurants, quirky shops, and more. The hotel features valet parking and self-parking in a covered garage, multilingual staff, ATM, and three on-site restaurants. Enjoy the rooftop heated outdoor lap pool and sundeck, along with 24-hour Hyatt StayFit gym.

Grand Hyatt San Antonio
600 E. Market Street
San Antonio, TX  78205
(210) 224-1234
sanantonio.grand.hyatt.com

Rate
Choice of Standard Room (King or Double) $165.00* per night + taxes

*The 4p- Support Group rate is good for 3 days before and 3 days after conference dates, based on hotel’s availability. Rate based on double adult occupancy, exclusive of adults with 4p-. Inform hotel directly of any special needs.

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

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

Discounted Self Parking at $20.00 and Valet at $30.00 plus tax per day with in and out privileges.

Transportation

The San Antonio International Airport (SAT) is 10 miles/11 minutes from the hotel.

Transportation to and from the San Antonio Airport is the responsibility of the conference attendees. Helpful links for various transportation companies are below. Feel free to contact conference hosts (see page 4) for any questions or assistance in securing transportation to the hotel.

SuperShuttle
http://group.supershuttle.com/group-page/4p-support-transportation/
(must book in advance for group rate)

Uber
Available in San Antonio

VIA Metropolitan Transit
viainfo.net

MAKE A HOTEL RESERVATION
Make your individual hotel reservations directly through our direct link:

4p-supportgroup.org/Hyatt-Reservations

For the 4p- Support Group rate, reserve by: July 2, 2018, 5:00 pm CST.

Please note:
The hotel has reserved rooms at our special conference rate of $165 per night (called a block of rooms). Once these block 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 July 2 date only refers to how long our special conference rate will be available.
SAN ANTONIO VISITOR INFORMATION

Visitor Websites
visitsanantonio.com
sanantonio.gov/visitors
thesanantonioriverwalk.com
where to dine

Walking / Riverboat Distance

1. Grand Hyatt
   sanantonio.grand.hyatt.com
2. Tower of the Americas
   toweroftheamericas.com
3. San Antonio River Walk
   thesanantonioriverwalk.com
4. The Alamo
   thealamo.org
5. The Doseum
  thedoseum.org
6. Brackenridge Park
   brackenridgepark.org
7. Japanese Tea Garden
   saparksfoundation.org/japanese-tea-garden
8. San Antonio Zoo
   szoo.org
9. Witte Museum
   wittemuseum.org
10. San Antonio Botanical Garden
    sabot.org

Hospitals

11. The Children’s Hospital of San Antonio
    333 N. Santa Rosa Street
    S.A., TX 78207
    (210) 704-2011
12. Baptist Medical Center
    111 Dallas Street
    S.A., TX 78205
    (210) 297-7000

Short Drive

- Natural Bridge Caverns
  (33 minute drive)
  naturalbridgecaverns.com
- SeaWorld San Antonio
  (26 minute drive)
  seaworld.com/san-antonio
- Six Flags Fiesta Texas
  (26 minute drive)
  sixflags.com/fiestatexas
- Morgan’s Wonderland
  (23 minute drive)
  morganswonderland.com

Airport

San Antonio International
Airport (10 miles from hotel)
sanantonio.gov.sat

Please note that San Antonio traffic and travel times can be unpredictable. Therefore, it is recommended to utilize a travel app or go to: ksat.com/traffic for the most updated traffic conditions.

Local Host Families

Stephanie Benson
stephbenson1@gmail.com
(361) 318-4435
Sylvia Renfro
Region4@4p-supportgroup.org
(936) 232-4068

Regional Director

Sylvia Renfro
Region4@4p-supportgroup.org
(936) 232-4068
### Wednesday, July 25, 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00a-4:00p</td>
<td>Research Workshop For genetic counselors, doctors &amp; scientists researching 4p-/WHS (Must be pre-registered)</td>
</tr>
<tr>
<td>11:00a-5:00p</td>
<td>Conference Check-in (Bonham Foyer) Packet pickup and conference updates Resource Fair - featuring products, information and services for people with special needs. Personalized Family Photos</td>
</tr>
<tr>
<td>4:00p-5:30p</td>
<td>First Time Attendee Session Intimate gathering to provide one-to-one introductions, overview of conference schedule and events, and introduction to 4p- Support Group</td>
</tr>
<tr>
<td>6:00p-9:00p</td>
<td>Welcome and Meet &amp; Greet Introductions Raffle Photo Booth Light Dinner</td>
</tr>
</tbody>
</table>

### Thursday, July 26, 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00a-11:00a</td>
<td>Late Conference Check-In</td>
</tr>
<tr>
<td>9:00a-2:00p</td>
<td>Free Time to Explore River Walk Lunch on your own</td>
</tr>
<tr>
<td>3:00p-9:00p</td>
<td>Family Fun Day Trip to Morgan’s Wonderland, a fully accessible amusement park Traditional Group Photo at Entrance Dinner and Transportation Provided</td>
</tr>
</tbody>
</table>

### Friday, July 27, 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30a-5:30p</td>
<td>Childcare/Sibling Activities Closed for lunch from 11:30a - 12:15p</td>
</tr>
<tr>
<td>9:00a-9:10a</td>
<td>President’s Welcome</td>
</tr>
<tr>
<td>9:10a-10:15a</td>
<td>Keynote Speaker  Major Kim “Rooster” Rossiter, USMC, Ainsley’s Angels of America</td>
</tr>
<tr>
<td>10:00a-2:00p</td>
<td>SibShop (Must be pre-registered)</td>
</tr>
<tr>
<td>10:15a-10:30a</td>
<td>Break</td>
</tr>
<tr>
<td>10:30a-11:30a</td>
<td>WHS: Latest News, Updates and You Dr. John C. Carey</td>
</tr>
<tr>
<td>11:30a-12:15p</td>
<td>Childcare Closed for Lunch</td>
</tr>
<tr>
<td>11:30a-12:30p</td>
<td>Complimentary Boxed Lunch</td>
</tr>
</tbody>
</table>

### Saturday, July 28, 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30a-3:00p</td>
<td>Childcare/Sibling Activities Closed for lunch from 12:30p-1:15p</td>
</tr>
<tr>
<td>9:00a-2:30p</td>
<td>Sibling Outing San Antonio Zoo (Must be pre-registered)</td>
</tr>
<tr>
<td>9:00a-10:00a</td>
<td>4p- Support Group Family Meeting</td>
</tr>
</tbody>
</table>

### Saturday, July 29, 2018

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:00a-10:00a</td>
<td>Spiritual Gathering</td>
</tr>
<tr>
<td>12:00p</td>
<td>Hotel Checkout</td>
</tr>
</tbody>
</table>

Please note that this schedule is subject to change. Please check our website for the most current schedule: [4p-supportgroup.org](http://4p-supportgroup.org)
Major Kim “Rooster” Rossiter is an active duty US Marine with over two decades of enlisted and officer service in North Carolina, Washington DC, Virginia, California, Okinawa, Africa, Korea, Norway, and is a combat veteran of Operation IRAQI FREEDOM. In addition to serving as the President of the Ainsley’s Angels of America, he is also a special advisor to many other adaptive sports organizations across the country. He and Lori, his wife of 20 years, hail from Lake Charles, Louisiana, and are parents to Briley, Kamden, and the namesake for Ainsley’s Angels, the late Ainsley Rossiter.

Major Rossiter’s daughter Ainsley was diagnosed with infantile neuroaxonal dystrophy (INAD) at age three, a rare pervasive developmental disorder that affects the nervous system. Ainsley went for her first run in 2008 pushed in a wheelchair by her father. Though she could not communicate verbally, her family immediately knew that they had found something she loved. Ainsley completed her 100th race before passing away in February 2016. Major Rossiter, who wasn’t a runner until he started running with Ainsley, pushed her in her signature pink wheelchair in the majority of those races. Ainsley’s 14-year-old sister, Briley, also pushed Ainsley in some of her races. The experience running with Ainsley was so life-changing that Major Rossiter and his family felt compelled to share it with others, through the creation of Ainsley’s Angels of America.

In addition to ensuring everyone can experience endurance events, Ainsley’s Angels of America aims to build awareness about America’s special needs community through inclusion in all aspects of life. Serving as advocates to providing education and participating as active members in local communities, we believe everyone deserves to be included.

Major Kim “Rooster” Rossiter
USMC
Founder and President of Ainsley’s Angels of America

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 is the Co-Medical Advisor of the 4p- Support Group and follows the oldest known living patient with the condition (she’s in her 60s). 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, and 2017 (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.

“I am a living patient with the condition...”

John C. Carey, MD

Dr. Calhoun completed her fellowship at the University of Utah within close proximity to mentors that include John C. Carey, MD and Sarah T. South, PhD.

Dr. Calhoun has played important roles in co-chairing and co-organizing several 4p- events. Specifically, she assisted at the informal “meet and greets” between clinicians and families at the 2010 National Conference (Salt Lake City, UT) and the Research Workshops over the last 6 years. In 2010 Dr. Calhoun became the current 4p- Support Group Medical Advisor and Co-Chair of the 4p- Scientific Advisory Board.

During the 2012, 2014 and 2016 4p- National Conferences, Dr. Calhoun had the opportunity to personally meet and clinically evaluate over 60 individuals with 4p-, discussing medical histories, previous test results (including karyotype and FISH), and clinical utility of undergoing testing with newer technologies (including chromosomal microarray analysis). These 60 individuals ranged in age from infancy to a woman in her late 20s. It is unlikely that any other scientist and clinical geneticist has had such in-depth experiences with that many individuals who have this condition. The culmination of these experiences have uniquely positioned Dr. Calhoun to comprehend the medical, natural history of 4p- as well as the psychosocial, familial, and societal implications a diagnosis has on the families. Furthermore, she is in a position to disseminate this information to her genetics colleagues, both in the US and abroad, so that all families with a diagnosis undergo improvements in patient care and also, possibly, quality of life.
FAMILY FUN DAY
MORGAN’S WONDERLAND
Thursday, July 26, 2018

Morgan’s Wonderland is the world’s first theme park designed with special-needs individuals in mind, and that everyone, regardless of age or ability, is included. Every element of the park is wheelchair accessible.

Registered conference attendees will be provided transportation, dinner, and full access to this 25-acre theme park at no extra charge.

Please note: Family Fun Day will be held at Morgan’s Wonderland, which is the theme park. Morgan’s Inspiration Island is the water park and is not part of our Family Fun Day/park buy-out.

For more information go to: MorgansWonderland.com

Schedule

3:00p ...................... Depart Hotel via buses (handicap accessible)
3:40p - 4:00p .......... Gather in front of Morgan’s Wonderland for our traditional group photo
4:00p - 5:00p .......... Enjoy dinner in the Event Center
5:00p - 8:00p .......... Park buyout begins. Explore all the fun that Morgan’s Wonderland has to offer, including rides, playscapes, gardens and other attractions - with no lines!
8:00p ..................... Depart Morgan’s Wonderland
9:00p ..................... Arrive at Hotel

Optional Thursday Daytime Pricing

Families who wish to visit Morgan’s Inspiration Island** and/or Morgan’s Wonderland prior to 3:00p on Thursday, may purchase special discounted tickets (transportation on your own). You have the option to buy tickets for only Morgan’s Wonderland (theme park), only Morgan’s Inspiration Island* (water park), or both Morgan’s Wonderland and Morgan’s Inspiration Island. Special pricing is good only for Thursday, July 26.

*Note: By purchasing discounted tickets for Morgan’s Inspiration Island, you agree to exit the park by 2:30p.

Morgan’s Wonderland Only (10:00a - 3:30p) ........................................... $9
Morgan’s Inspiration Island Only (11:00a -2:30p) ............................... $10
Both Morgan’s Wonderland & Inspiration Island................................. $19
Individual with 4p- or other special needs ............................................ FREE
Children age 2 and under ................................................................. FREE

Discounted tickets must be purchased at the time of registration and are good only for Thursday, July 26

“This is the world’s most ultra-accessible theme park ever

Inspired by his daughter, Morgan, who lives with cognitive and physical challenges, Gordon Hartman sold his home-building business in 2005 to create Morgan’s Wonderland, a 25-acre theme park in San Antonio, Texas, for individuals with special needs...”

USA Today Reader’s Choice 2017 Best New Attractions
2nd Place: MORGAN’S INSPIRATION ISLAND

“Morgan’s Inspiration Island opened in the summer of 2017 as the world’s first ultra-accessible splash park, where guests of all ages and abilities can cool off and have fun”
CHILDCARE & SIBLING ACTIVITIES AT HOTEL
Childcare & sibling activities will be available for individuals with 4p- and their siblings. There is no charge for the childcare and all ages are welcome.

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

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

SIBSHOP WORKSHOP at Hotel
Friday, July 27 - 10:00a - 2:00p
Ages 7-12
$10 per child – includes lunch
Space limited | Must pre-register

Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so-good thing, and for many, somewhere in-between. 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.

SibShop Presented by CRIT USA

The Children’s Rehabilitation Institute of TeletonUSA (CRIT USA) is a state-of-the-art pediatric rehabilitation facility located in San Antonio. CRIT offers services to children and families from birth to 18 years of age with neurological and musculoskeletal disabilities regardless of a family’s ability to pay. For more information about CRIT, please visit their website: teletonusa.org

SIBLING OUTING*
Saturday 28, 2018
9:00a - 2:30p

OUTING FEE: $23
Sibling Age: 8+
Must pre-register

Cost includes transportation, admission, and lunch in the zoo.

See San Antonio’s premier zoo, which welcomes more than a million visitors each year! You will experience more than 750 animal species from around the world on 56 acres. Check out the largest collection of birds in the world; large animals including tigers, hippos, zebras, and elephants; a number of different monkeys; and daily talks by the experts. In the Africa Live section, look through underwater viewing windows to watch hippos, crocodiles, and African cichlid fish in the water. Get a feel for the rainforest at The Amazonia exhibit, and much, much more!

More info: sazoo.org

*This outing is offered only to the siblings, ages 8+, of 4p-individuals. We kindly request no parents participate in this outing, so that siblings can have a day to share in fellowship with other siblings. Chaperones will be available at a ratio of 1:3 for those participants ages 8-15. Participants ages 16+ will have a chaperone at a ratio of 1:8.
**2018 CONFERENCE REGISTRATION**

<table>
<thead>
<tr>
<th>Registration Fees</th>
<th>Early Bird prior to March 31</th>
<th>April 1 - June 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent/Guardian</td>
<td>$75</td>
<td>$100</td>
</tr>
<tr>
<td>All other adults (18 &amp; over)*</td>
<td>$125</td>
<td>$150</td>
</tr>
<tr>
<td>Children ages 11-17*</td>
<td>$75</td>
<td>$100</td>
</tr>
<tr>
<td>Children ages 2-10*</td>
<td>$50</td>
<td>$75</td>
</tr>
<tr>
<td>4p- Individuals (any age) &amp; Children under 2</td>
<td>FREE</td>
<td></td>
</tr>
<tr>
<td>Registration late fee per family if received after June 8</td>
<td>$60</td>
<td></td>
</tr>
</tbody>
</table>

*Fees determined by age as of July 25*

Cancellation policy: Registration fees are fully refundable until June 8, 2018. If you must cancel after June 8, all registration fees made will be donated to the 4p- Support Group’s conference scholarship fund. This donation will qualify as a charitable donation.

For information on our conference scholarship fund, go to: http://4p-supportgroup.org/conference-scholarship

---

**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/

---

**4P- SUPPORT GROUP MERCHANDISE**

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. Additional merchandise will be available for purchase during the conference. Cash and credit cards accepted (no checks please).

---

**CONFERENCE CONTACTS**

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

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

---

**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:**

Sylvia Renfro  
Region4@4p-supportgroup.org  
(936) 232-4068

Thank you in advance for your support!
2016 CONFERENCE
Woodland Hills, CA
75+ Families