



Thank you for registering for IRSF's very important 26<sup>th</sup> Annual Conference. This year's conference is located in Colorado Springs, Colorado, May 28 - May 31, 2010 at the [Cheyenne Mountain Resort](http://www.cheyennemountainresort.com). A full conference program can be downloaded from [www.rettsyndrome.org/conference](http://www.rettsyndrome.org/conference) so that you can map your session attendance plan in advance. Though last minute changes may be made to our very full schedule, reviewing the program ahead of time will ensure you get to your priority lectures, workshops and panels. Also, be sure to read session descriptions carefully as some speakers have indicated materials that you should bring or complete in advance to enrich your session attendance.

Please note that registration fees do not include travel and hotel accommodations; these arrangements must be made separately. We have negotiated special room rates at the Cheyenne Mountain Resort and encourage you to reserve early while rooms are available.

## REGISTRATION

Full conference registration fees include:

- All registration and conference materials
- Access to all sessions, workshops, exhibitors, and IRSF Bookstore (Fri-Mon)
- Friday: dinner, welcome orientation, and Crackerbarrels
- Saturday: breakfast, lunch, dinner, plus evening coffee and dessert Tribute Reception and auction
- Sunday: breakfast and lunch
- Monday: Crackerbarrels and Bookstore

Single day conference registration fees include:

- Registration and conference materials
- All-session, workshop, exhibitor and IRSF Bookstore access for that day
- Breakfast and lunch for that day (Saturday single-day registration includes dinner. Tribute Reception tickets can be purchased separately for \$15)

## TRIBUTE RECEPTION:

IRSF will host a coffee, dessert, and cash bar Tribute Reception, award ceremony, silent auction and entertainment on the evening of Saturday, May 29<sup>th</sup> at the Cheyenne Mountain Resort. Attendance is included with your paid full-conference attendance package. Our girls and women with Rett syndrome are also welcome at no charge. Single-day conference attendees and non-conference friends and traveling companions are welcome to purchase tickets at \$15 per person *while tickets are available*. Dress to impress, but formal attire is not expected. Entertainment and dancing will follow the Tribute and Awards ceremony.

## SILENT AUCTION

Donate an item for the Silent Auction - gifts for our girls and their caregivers, weekend vacation homes or getaway certificates, gift baskets, and fine wines are always desirable and the proceeds go to a good cause! Mail in advance to our local parent contact Carrie Rose or bring your item to the registration desk upon your arrival. The Silent Auction will run in the Bookstore all day Saturday, and close at the Tribute Reception Saturday evening. Email [jgrammer@rettsyndrome.org](mailto:jgrammer@rettsyndrome.org) or call 1.800.808.RETT (7388) with questions or for Ms. Rose's mailing address.



## KEEPSAKE PROGRAM JOURNAL, TRIBUTE VIDEO, PHOTO BUTTONS

- Place a special message in the IRSF 26th Anniversary Helping Hands Keepsake Program Journal in honor of the Rett angel that has touched your life. The Helping Hands Journal will be distributed at Conference, and will be downloadable from our website after conference. Tell grandparents, family members, friends, co-workers, doctors, teachers and therapists about this opportunity to write a poem, share a loving thought, a message of hope, feature a scanned picture or piece of school/artwork, and/or advertise a business - ideas are endless! Visit the website [www.rettysyndrome.org/conference](http://www.rettysyndrome.org/conference) or contact Jenni Grammer at [jgrammer@rettysyndrome.org](mailto:jgrammer@rettysyndrome.org) or 1.800.818.RETT (7388) for ad rates and details. **Ads MUST be finalized by Friday, April 23, 2010.**
- Include your child in the much-anticipated Tribute Video. Email a .jpeg picture or short movie file attachment to [lhayden@rettysyndrome.org](mailto:lhayden@rettysyndrome.org) with "Conference Tribute Video" in the subject line **by Monday, April 26, 2010.** Remember our theme "*Ain't No Mountain High Enough*" when choosing what pictures to include!
- Proudly wear a **photo button** of your child throughout the conference! Mail a 3" photo of your child to IRSF, Attn. Lisa Hayden at 4600 Devitt Drive, Cincinnati, OH 45246 or email a .jpeg to [lhayden@rettysyndrome.org](mailto:lhayden@rettysyndrome.org) **before Monday, April 26, 2010.** Buttons will be ready for pickup at the onsite registration desk.

## DRESS

We encourage you to dress comfortably for the day sessions, and wear something a little nicer for the Saturday Tribute Reception. The weather in Colorado can still be cool in the month of May, and conference rooms sometimes run cool, so wear layers. Wear comfortable shoes - you can log miles on your feet at a busy conference. Cheyenne Mountain Resort has swimming pools, a family water play area, and an on-property lake with paddle boats so don't forget your suit and sunscreen.

## SPECIAL THOUGHTS ON CHILDCARE/RESPITE

On a tender note, we must remind you that the conference sessions are for paid registered attendees only; and no children under 12 will be permitted at all in the sessions. This weekend is a fast-paced event intended to educate all attendees, provide you with an opportunity to interact with other members of the RTT community and provide some respite time away from the daily challenges of caregiving. This is hard to do if you are juggling family demands. However, we also want you to feel welcome to bring your family members as Colorado is a great getaway vacation spot for families. If you choose to do so, please arrange childcare in advance so you will be free to attend sessions and network with other attendees. Many couples trade off these responsibilities throughout the weekend.

We will offer onsite respite during session hours for our children with Rett syndrome only. There is a minimal hourly fee. Preregistration is required and charged whether used or not since we must staff with a combination of licensed RN and CNA care providers and volunteers. Space is limited. Please call the IRSF office at 1.800.818.RETT (7388) for details and ask for Lisa Hayden.

## HOTEL/RESORT INFORMATION

The IRSF 26th Annual Conference will be held at the Cheyenne Mountain Resort, 3225 Broadmoor Valley Road, Colorado Springs, Colorado 80906. We have negotiated an incredible room rate of \$129 one adult/\$145 two adults (per night) for all conference registrants, subject to availability. There is no fee for parking. You will find a link to resort reservations off of our website [www.rettysyndrome.org/conference](http://www.rettysyndrome.org/conference). The Cheyenne Mountain Resort is a unique location that offers many special amenities including Championship golf, pools, Kids Splash Park, 35-acre lake, tennis courts, full-service health club, and jogging paths. There are additional fees for some of these activities. We hope you can come a little early, or stay a few extra days, to rest and relax. The Cheyenne Mountain



Resort is also offering a special rate of \$129 per night plus \$15 resort fee immediately before and after our conference to registered attendees only, subject to availability. Contact the resort to find out more.

### MEALS

The meals that are included with your conference registration fee will be onsite at the *Mountain View* restaurant. The Lansdowne has generously offered to serve girls and women with Rett syndrome at the *Mountain View* restaurant as their guest at no charge when accompanied by a paid conference attendee. All other guests with you may also dine at the Mountain View restaurant and either pay directly or have meals charged to their room. We would like mealtimes to be a comfortable opportunity for you to spend time with your family as well as new friends made at the conference. Other restaurants are onsite at the Cheyenne Mountain Resort, as well as nearby Colorado Springs. Please visit their website for more information [www.cheyennemountain.com](http://www.cheyennemountain.com), and call for buffet and a la carte menu prices.

*Mountain View* Restaurant Hours are:

Breakfast 6:30am - 10:00am (including Sunday brunch 10am-2pm)

Lunch 11am - 2pm

Dinner 6pm - 10pm

### TRAVEL AGENT

Maryann Sabo, a Rett syndrome parent and seasoned travel agent with Sato Travel, has attended numerous IRSF conferences. She is well-equipped to answer all of your travel questions, and we encourage you to utilize her expertise to plan your travel. She can be reached via telephone at 1-800-872-7286 or 703-931-4290 or email her at [MSabo@CWTSatoTravel.com](mailto:MSabo@CWTSatoTravel.com). She has access to special rates with all airline carriers and is able to customize your itinerary based upon your individual travel needs.

### LOCATION

Located in Colorado Springs, Cheyenne Mountain Resort is just a 20-minute drive from the Colorado Springs Airport, offering 120 daily flights from 10 commercial airlines. The property is approximately a 1 ½ - 2 hours drive from Denver and Denver International Airport. Travelers in/out of Denver International will need to arrange for personal transportation or car rental.

### SHUTTLE INSTRUCTIONS from/to the COLORADO SPRINGS AIRPORT

Cheyenne Mountain Resort will offer conference attendees plus their travel companions complimentary, scheduled shuttles from the [Colorado Springs Airport](#) to the resort and for your return to that airport Friday, Saturday, Sunday and Monday. **\*\*Please note that the resort shuttles are not wheelchair accessible\*\***

Please contact the Bell Desk in advance of your arrival at 719-538-4020. The Bell Desk will ask for arrival and departure information and will have the shuttle set up for you.

### SHUTTLE RECOMMENDATION from/to the DENVER INTERNATIONAL AIRPORT

Shuttle from Denver to Colorado Springs is \$65 one way per person, and a round trip ticket is \$90 per person. Please call or email Colorado Springs Shuttle to make reservations: [reservations@coloradoshuttle.com](mailto:reservations@coloradoshuttle.com) or call (719) 687-3456



#### **DRIVING DIRECTIONS from the Colorado Springs Airport**

1. Go west on Mark Proby Pkwy approximately 3 miles to Academy Blvd.
2. Turn left on Academy and stay in the left-hand lane.
3. Follow Academy approximately 4 miles to Highway 115.
4. Exit north at Highway 115.
5. Proceed approximately one mile to Cheyenne Mountain Blvd.
6. Turn left on Cheyenne Mountain Blvd. and go one block to Broadmoor Valley Rd.
7. Turn left and go three blocks to Cheyenne Mountain Resort.

#### **DRIVING DIRECTIONS to Cheyenne Mountain Resort from I-25**

1. Exit 138 - Circle Drive.
2. Turn West (toward the mountains).
3. Two miles to Highway 115 South - Canon City.
4. Continue under the overpass and LEFT turn onto ramp.
5. First traffic light, Cheyenne Mountain Boulevard, turn RIGHT.
6. Take the first LEFT, Broadmoor Valley Road - (Resort's sign on the corner).
7. One half mile to Cheyenne Mountain Resort - Main Entrance on the LEFT.

#### **LOCAL ATTRACTIONS**

**Barn Tour at Pikes Peak Therapeutic Riding Center** - [www.pptrc.org](http://www.pptrc.org) - 13620 Halleluah Trail; Elbert, CO 80106  
**Friday May 28, 2010** - PPTRC Program Director Nancy Beers will offer hourly guided tours of their facility, including an opportunity to observe a Hippotherapy session, on Friday May 28 at 9 am, 10am, 11 am, and 12 noon. A minimum of 2 and a maximum of 10 visitors per group is requested. Please dress in layers with closed-toed shoes. We ask that you observe our confidentiality policies by not discussing any rider specifics or taking photographs of riders. There is no smoking on the property. Please sign up for a time slot in advance with IRSF ([admin@rettsyndrome.org](mailto:admin@rettsyndrome.org)). Maps are available on the PPTRC website [http://www.pptrc.org/About\\_PPTRC/map\\_to\\_pptrc.htm](http://www.pptrc.org/About_PPTRC/map_to_pptrc.htm) It is approximately a 40 minute drive to PPTRC from the Cheyenne Mountain Resort. See you in the barn!

In 2009, Outdoor Magazine ranked Colorado Springs America's #1 city. Our family has lived in Colorado Springs off and on for six years. We have come to love Colorado for its rich history, clean mountain air and an abundance of inclusive activities for our family. Here are some must do activities if only here for the weekend. All are free and open to the public. Highlights of Colorado Springs, close to the Cheyenne Mountain Resort, accommodating to the disabled population:

- **United States Air Force Academy Visitors Center** - be sure to include a tour of the Cadet Chapel. (Wheelchair accessibility in on the north side of the chapel.) While driving through the Academy reservation, watch your speed limit as well as for elk, mule deer, wild turkeys, coyotes, brown bears and mountain lions. If you would like a hike, the 13-mile Falcon Trail is a fantastic way to view the Academy, however, it is not wheelchair friendly.



- **Cheyenne Mountain Zoo** - Cheyenne Mountain Zoo makes every effort to accommodate visitors with disabilities. People with disabilities and their caregiver can get admission for \$5.00 each  
<http://www.cmzoo.org/guestInformation/hoursAdmission/>
- **U.S. Olympic Training Center** - The U.S. Olympic Complex in Colorado Springs is the headquarters for the U.S. Olympic Committee administration and the Olympic Training Center programs. Tours are free and are given daily. The tour includes where the athletes live, dine and train. The tour is completely wheelchair accessible. The tour lasts about an hour and you can usually see a few athletes training.  
<http://www.teamusa.org/>
- **Garden of the Gods Park** - a registered National Natural Landmark. Featuring 300' towering sandstone rock formations against the backdrop of snow-capped Pike's Peak and brilliant blue skies. You can drive through the park and experience the beauty or hike on the numerous trails. Less than 20 minutes from the conference site take a slow 30-minute drive through the park and witness spectacular red rock formations amidst pinyon trees. Both the Park and Visitor Center are Free and open to the public.  
<http://www.GardenOfGods.com>
- **Manitou Cliff Dwellings** - Take a trip into America's past. Preserved under a protective red sandstone overhang are authentic Anasazi cliff dwellings, built more than 700 years ago. Because of the slope of the dwellings, the steps and the narrow passages inside, the dwellings, themselves, are not accessible to wheelchairs. The entrance to the cliff dwellings - is wheelchair accessible by ramp from the parking lot. From that point the entire front of the dwellings can be seen. People in wheelchairs are admitted for free.  
<http://www.cliffdwellingsmuseum.com/>

Remember the altitude of Colorado Springs ranges between 6,035- and 7,200'. Newcomers may experience headaches and shortness of breath. Drink plenty of water (for example, increase to 8-10 glasses of water each day, and avoid beverages that dehydrate like sodas and alcohol), wear sunscreen to combat the more intense UVs at this altitude and enjoy yourself.

*The Huisingsh Family*  
*Conference Planning Committee member*  
*IRSF Family Advisory Board*

Additional Information can be found at these websites:

Visitor's bureau: <http://www.visitcos.com/>

City of Colorado Springs: <http://www.springsgov.com/SectionIndex.aspx?SectionID=5>

Minor league baseball team Colorado Springs Sky Sox are in town Memorial Day Weekend!  
<http://web.minorleaguebaseball.com/index.jsp?sid=t551>



### WEBCAST SESSIONS

NEW For those who cannot attend the conference in Colorado, **SATURDAY** sessions **ONLY** will be broadcast via LIVE webcast. You must register for the live streaming Saturday sessions at least 48-hours in advance, and a discount is offered for registrations before MAY 9, 2010

Webcast Registration includes:

\*(1) "virtual seat" to view live, in real-time, the conference sessions offered Saturday, May 29, 2010, between 8am and 6pm MOUNTAIN time.

\*PDF copies of Conference materials and the Helping Hands Keepsake Journal

\*IRSF will email information for internet, computer and audio requirements 4-weeks prior, and the actual session link and password 2 days prior, to the email address specified at the time of registration. See website for program and session details.

### QUESTIONS

If you have additional questions, please feel free to call the IRSF office at 1-800-818-RETT (7388).