

**The Support Organization for Trisomy 18,  
13 and Related Disorders (SOFT)  
welcomes you to its 30<sup>th</sup> Annual  
Conference in Tacoma, WA,  
July 20 – 24, 2016**



Contact the conference committee: [terrekrotzer@gmail.com](mailto:terrekrotzer@gmail.com)

[Conference Registration](#)

[Donate to Conference](#)

[Request Balloon Release](#)

[www.trisomy.org](http://www.trisomy.org)

V: 3-20-2016

## Tacoma: “The City of Destiny”



About Tacoma: Tacoma is known for its world-renowned glass art and its vibrant urban core is alive with culture. Find yourself surrounded by creativity and city sophistication when you eat, shop and stroll Tacoma’s downtown. The friendly city inspires many to celebrate the melding of old and new. See historic architecture amidst urban design.

The city’s many districts abound with culture. Stroll the museum district where you can explore art, glass and history. Wander amongst the eclectic mix of upbeat restaurants and music venues on South Avenue. Shop the unique boutiques in the historic Proctor and Stadium districts, which bustle with foot traffic.

**[Read more about visiting Tacoma!](#)**  
**[Information about Sea-Tac Airport \(includes transportation alternatives from airport to hotel\)](#)**

A *possible* source of financial assistance for attending the conference can be found at: **<http://joyfuljourneymom.com/ultimate-list-of-grants-and-resources-for-families-with-special-needs/>**

## ~~~~ Conference Overview ~~~~

<<< Register by Midnight, June 12, 2016, after which a \$25 late fee will apply >>>

**Conference Hotel:** The Conference will be held at the Hotel Murano, 1320 Broadway, Tacoma WA 98402. [For Internet Reservations use this link.](#) Telephone reservations can be made by calling 1-888-862-3255 and asking for the SOFT Conference rate of \$139. Hotel reservations should be made by June 26<sup>th</sup>, after which the room block will be released to the general public.

**Registrations - please note:** The hotel reservation and the conference registration are **two separate reservations**: Call the hotel for your room reservations and use the SOFT website to register for the conference, after registration opens. Please note when registering for the conference that age 12 and up are considered adults (except SOFT children, of course).

**Photographs:** The registration form found on [www.trisomy.org](http://www.trisomy.org) will prompt you to upload two photographs - one of your SOFT child (whether attending or not), for use during the conference and one of you or your family for inclusion in the conference roster provided to all attendees - so have those photo files ready when you complete the registration form.

**Check in:** After checking in to the hotel, go to the SOFT registration desk in the Bicentennial Pavilion, located across the courtyard, out the fourth floor door (see floor plans at end of this brochure). There, you can complete your conference check-in and receive your conference materials. The SOFT registration desk is expected to open at 1pm Wednesday. The complete list of open hours will be posted at the check-in desk.

**The Conference activities** will be held in the hotel's Bicentennial Pavilion – see the hotel floor plans at the end of this brochure for the Pavilion floor plan.

**The SOFT Stroll for Hope** is an annual conference fundraiser. Prizes for best dressed family, most pledges raised, and best decorated wheelchair or stroller will be awarded by the Cook Family. Meet in the rotunda area of the Pavilion and “weather permitting” we will stroll either there or in the courtyard area out front with many cheering us on. The Cooks will be Jonathan’s Fans, all decked out in rainbow, of course. For questions, please email Cindy Cook at [newbeg08@aol.com](mailto:newbeg08@aol.com).

[Make your pledge page and get started by clicking here.](#)

**Meals:** See the schedule of events (below) for the complete list of meals being served and included in your registration fee. When completing the **registration form** found on the SOFT website, please note that we ask you to state how many Prime Rib or Chicken or Vegetarian dinners will be desired for your adult members only.

**2016 SOFT Video Montage:** Be part of the "**SOFT Friends**" DVD, in memory of Kari Holladay, honoring all our children through pictures and music! Please submit 3-4 pictures per child. Include your child's name and diagnosis, parent names, birth date & death date (if applicable), and if you are attending the conference. You don't have to attend in order to include your child's photos. Please submit your pictures by **June 1, 2016** (earlier is preferred). Photos received after June 1 cannot be incorporated in the video. Pictures will not be returned, so please do not send your original, one of a kind picture!

You can share your photos in three ways: **1) Upload pics** at <http://www.softannualvideo.com> **2) Email pics** to Kris at [holladay2go@hotmail.com](mailto:holladay2go@hotmail.com) (include SOFT in subject line to preclude its going to a junk file) or **3) Mail to:** Kris Holladay, 1522 E. Garnet Avenue, Mesa, AZ 85204. ALL varieties of photos are appreciated: touching, funny, sweet, silly, heartwarming, accomplishments and your SOFT child with siblings & families, etc. SHORT videos (1-2 min) are great! Send video, YouTube link or questions to Kris' email.

**Auction:** Will be held on Saturday evening at 6:00pm in Pavilion A, G & D. Please bring items to donate as well as cash, checkbook and credit cards! Turn in auction items when you register with SOFT at the hotel or mail them **by June 20th** to: Terre Krotzer, 1820 216th Ave Ct E, Lake Tapps, WA 98391. We love auctioning handmade items, baskets of treats from your area, home décor, art work, SOFT-related items, jewelry, gift certificates, and signed sports memorabilia. It's a perfect time to regift; we won't tell!

**Quiet Room:** A special quiet room will be provided in the Pavilion for sharing the memories of our Angel Children, from 8am to 10pm Wednesday through Friday and 8am – 8pm on Saturday. Bring photos, photo albums, scrapbooks or any other mementos to share and be sure to label your items with your name and contact information.

**Childcare:** While you attend conference events, childcare is available as described in the registration form. Please check your conference materials for the room location, and don't forget to bring any special items your child will need, such as nap blankets/pillows or special foods and medications.

**Need Financial Assistance to Attend?** The **Conference Assistance Fund, in memory of Joey Watson**, provides a limited amount of financial assistance to those needing assistance to attend the conference. [Click here to apply \(note the deadline is May 15th\).](#)

**SOFTwear:** T-shirts celebrating the conference are available - order them on the registration form. Please order when registering, so that we will have what you want, when you arrive. If you decide to order T-shirts AFTER you have registered, submit a second registration form, ordering only the T-shirts. We'll already have your other information. Put a note that it's only a T-shirt order in the COMMENTS box. SOFTwear orders must be placed by midnight, June 7th, along with the registration form. Some extra shirts in common sizes might be available at the conference, but don't depend on it. Order your shirts and wear the logo!

## ~~~~ Conference Event Schedule ~~~~

**Tuesday:** If you arrive in Tacoma early, SOFT will have available a limited number of discounted tickets to the Tuesday night ball game (Tacoma Rainiers vs Oklahoma City Dodgers), at Cheney stadium. These tickets are only \$7.50 and are available from the stadium's "will-call" service. Be sure when speaking to them that they understand you are with the SOFT group..

**Wednesday: 7:30 – 9:00pm** Ice Cream Welcome Social. Attendees are invited to the Pavilion Room A for a casual meet-and-greet social evening. We will have ice cream sundaes for all and we will be premiering the Kari Holladay SOFT Friends Video during the evening. A must see for all attendees. [holladay2go@hotmail.com](mailto:holladay2go@hotmail.com)

**Thursday: 7:30 – 8:45am** Continental Breakfast in Pavilions A & G  
**9:00 – 3:45** Workshops as listed below.

### **9:00-10:00am**

1a Guardianship & Trust -. When your child turns 18 - An Attorney will discuss how to apply for Guardianship and understand why it's necessary. She will also discuss how a Trust can be helpful. Nancy Lee, Attorney

1b Tris Project - This session will provide an overview of activities of the Tracking Rare Incidence Syndromes (TRIS) project during the past 12 months highlighting areas of data analyses and results and recently published articles. Dr. Deborah A . Bruns

1c Digital Scrapbooking - Learn how to create amazing professionally-bound photo books of your treasured family photos using your computer rather than boxes full of scissors, paper and glue. Chelsea Dye

1d Occupational Therapy/Floor time - Part 1 - Introduction to the Floor time model of playful engagement for developing social & emotional development. Exploring its impact on cognition and the ability to be engaged in the world. Joyce Vipond OT

### **10:05 - 11:05am**

2a Occupational Therapy/Floor time engagement -part 2 - Continuation..Live treatment demonstrations, videos and practical ideas for engaging your children. Joyce Vipond OT

2b Genetics -The goals of the workshop are to describe the syndrome patterns of trisomy 13 & 18 and address the questions of the attendees.Dr. John Carey

2c 'Tell Your Story' - Making a Sash - loss of a child -Sheryl Crosier

2d Transitioning Services-When your child turns 18. Discuss how parents can find services and understand how to go through the process. Tami McGrath

**11:10am - 12:10 pm**

- 3a Bridging-Experiencing Loss & Going Forward-Professional Counselor from Mary Bridge Children's Hospital who works with families and their loss.
- 3b I.E.P.-When your child needs an IEP for school. Understanding how it works and communicating and advocating for your child's needs while in school. Shane Baguyos-Orting School District-Student Services
- 3c Vision, light sensitivity and seizures, New information on how indoor and outdoor light affects your child and seizures. Detailed handouts with information on how to correct this newly discovered photosensitive issue.. Benefits for Mom and Dad too. Dr. Steve Cantrell

**12:15 - 1:10 Lunch Break.** Pavilions A & G (Chapter Chairs in Pavilion D)

**1:15 - 2:15p.m.**

- 4a Hosting a SOFT Conference: Bringing SOFT Conference to your area! Come and learn how you can host a SOFT Conference! 2017, 2018 - Jim Dye
- 4b Augmentative & Alternative Communication - Discussion on how the effective use of AAC, Augmentative Alternative Communication, can be used to help with your child and communication. Use of mobile technology. Marci Revelli, ST
- 4c Essential Oils & Aromatherapy- A simplified introduction and easy to understand 'how to' use essential oils & aromatherapy and how this can be used for your family. Handouts will be provided. Amber Duncan, Clinically Certified & Licensed Aromatherapist who specializes in helping pregnant women, children and families.

**2:20-4:00**

- 5a Dad's Only - Sharing Workshop
- 5b Mom's Only - Sharing Workshop

**6:00 - 11:00pm** Join us for the Welcome Dinner which will include the annual **SOFT Parade of Stars** and the **Children's Candle Ceremony**, to be held in Pavilions A, G & D. We will hear from our Keynote Speaker followed by an evening of music, dancing and celebration.

**Friday: 7:30 – 9:00am** Full Breakfast in Pavilions A & G, followed by the SOFT Business Meeting (9-11am). Think about running for membership on the SOFT Board of Directors!

**1:00 – 5:00pm** Medical Clinics, for families bringing a SOFT child to conference, will be held at [Mary Bridge Children's Health Center, 311 South L Street, Tacoma, WA 98405](http://Mary Bridge Children's Health Center, 311 South L Street, Tacoma, WA 98405). Please sign up early on the conference registration form, as these fill up fast. Don't forget to indicate your need for busing on the form! Meet outside the lobby doors at your assigned time to catch the bus.

The medical clinics being offered this year are as follows:

- |                             |                        |                      |                                 |
|-----------------------------|------------------------|----------------------|---------------------------------|
| <b>1 - Cardiology</b>       | <b>2 - Nephrology</b>  | <b>3 - Neurology</b> | <b>4 - Otolaryngology (ENT)</b> |
| <b>5 - Gastroenterology</b> | <b>6 - Orthopedics</b> | <b>7 - Genetics</b>  | <b>8 - Ophthalmology</b>        |

**9 - Audiology                      10 - Physical Therapy   11 - Occupational Therapy   12 - Speech  
13 - Pulmonology**

**1:00 - 4:30pm** Remembrance Outing, for families who have lost children, at Point Defiance Park

**12 - 4:00pm** Older Siblings Outing at 6 Flags Wild Waves Water Park (age 8+). Prices (TBA) will be discounted until May 31st at which time they will return to normal.

**12 - 4:00pm** Younger Siblings Outing, Tacoma Children's Museum (age 5 - 7). Prices (TBA) will be discounted until May 31st at which time they will return to normal.

**Friday evening:** Feel free to enjoy a Family Night Out with your family. This is an opportunity for your family to explore our wonderful city. A list of [recommended restaurants](#) can be found here. [A more complete list of restaurants is provided here.](#)

**If you prefer to stay in** you are invited to join us for some relaxing activities in the Hotel Pavillion.

**Saturday:            7:30 -9:00am** Continental Breakfast in Pavilions A & G  
**9:00-10:00am** *SOFT Stroll for Hope* - grab your costumes, decorate your wheel chairs and meet us in the Pavilion Rotunda.Tr

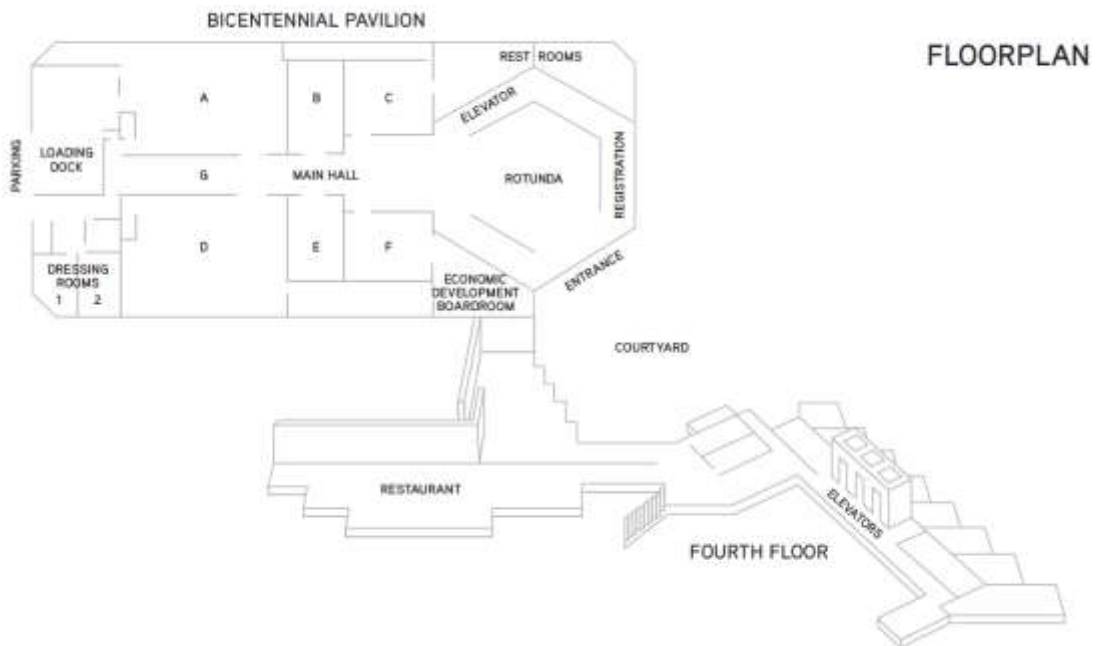
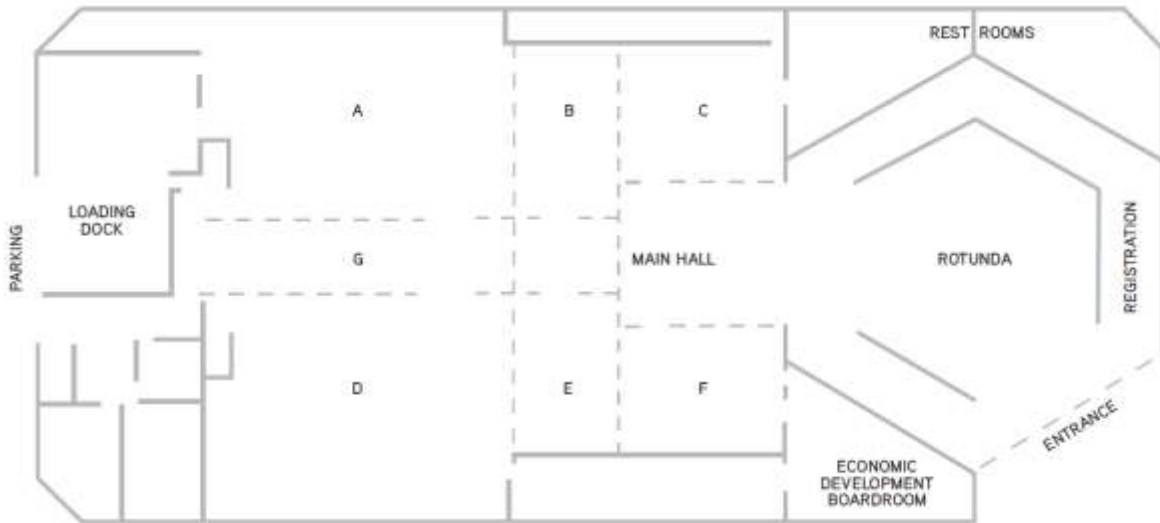
**10:30am** Board Bus for Picnic at Cheney Stadium

**11:00 – 3:00pm** SOFT Annual Picnic & Balloon Celebration at Cheney Stadium,  
Tacoma, WA

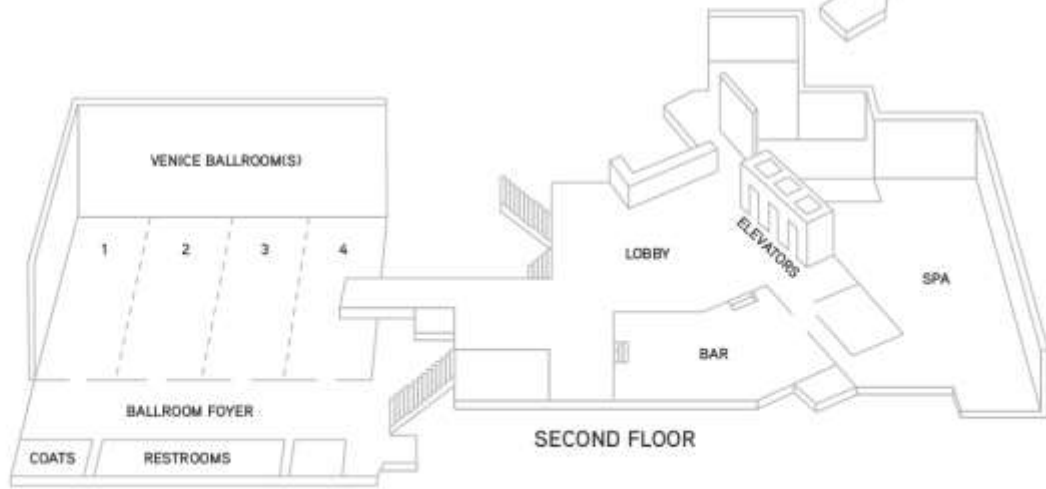
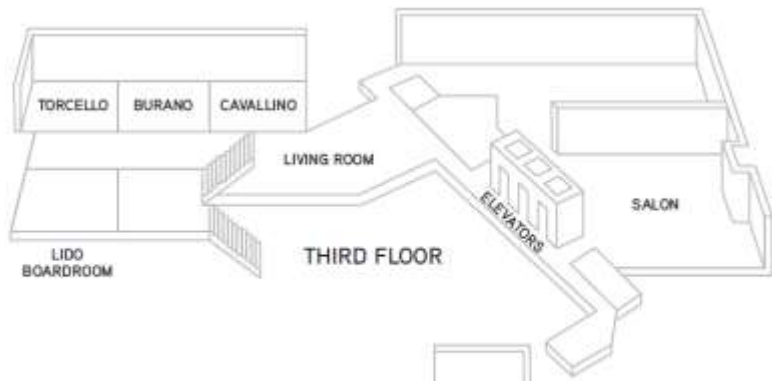
**6:00 - 10:00pm** PM – SOFT Auction in Pavilions A, G & D

**Sunday:            7:30 – 9:00am** Continental Breakfast & Conference Farewell in Pavilions A & G

~~~~ Hotel Murano Floor Plans ~~~~







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