

Conference Brochure Ann Arbor 2019

**SOFT's 33rd annual medical &
family conference,
in Ann Arbor, MI, July
17-21, 2019!**

**We're sorry, but registration is now
closed...**

**You are more than welcome to attend the
2019 SOFT Conference by registering at the
door, but the workshops and clinics are
subject to space availability and there may
not be meals at events where meals needed
to be ordered in advanced.**

Scroll down and use the blue links to view all conference
information!

[Click here to register for any aspect of the Conference,
and/or Balloon Celebration](#)

[Click here for an Application to become a Board Member.](#)

**Special Notice: Read this medical
alert, concerning the
Ann Arbor area and measles!**



The conference will be held at the [Ann Arbor Marriott Ypsilanti at Eagle Crest, 1275 South Huron St., Ypsilanti, MI, 48197.](#) Phone: 734-487-2000. [Click here](#)

[to book a room using the special \\$140 SOFT rate.](#) Our rate code is "SOFT." **This rate expires midnight June 24th, so don't wait!** And don't forget to register for the [Conference](#), in addition to your hotel registration!



[If you would like to donate funds to a specific conference activity, or to SOFT's operating or medical expenses, please click here.](#)



On-line Conference Registration Costs: Adult registration (age 12+) is \$145; children aged 5 – 11 are \$95. Children under 5 years old and SOFT children are free. Picnic-only registration is \$35 (adult, 12+) and \$20 (child, =>5). If attending ONLY Thursday's **Lunch & Workshops**, the cost is \$45. NOTE: After midnight, June 30, EST, the Adult registration cost will rise to \$165 as the hotel will have to rework their meal supplies and costs.



The SOFT Check-in Room will open at 1pm on Wednesday – location (TBA). Please check in as soon as you arrive so you can receive your conference bag which contains essential conference information and much more.

| MONTH | MEETING DATE | REGISTRATION DATE | DOCUMENT REVIEW DATE | REVISIONS DATE |
|-----------|--------------|-------------------|----------------------|----------------|
| JANUARY | JAN 26 | JAN 26 | JAN 26 | JAN 26 |
| FEBRUARY | FEB 23 | FEB 23 | FEB 23 | FEB 23 |
| MARCH | MAR 23 | MAR 23 | MAR 23 | MAR 23 |
| APRIL | APR 27 | APR 27 | APR 27 | APR 27 |
| MAY | MAY 25 | MAY 25 | MAY 25 | MAY 25 |
| JUNE | JUN 29 | JUN 29 | JUN 29 | JUN 29 |
| JULY | JUL 27 | JUL 27 | JUL 27 | JUL 27 |
| AUGUST | AUG 24 | AUG 24 | AUG 24 | AUG 24 |
| SEPTEMBER | SEP 20 | SEP 20 | SEP 20 | SEP 20 |
| OCTOBER | OCT 26 | OCT 26 | OCT 26 | OCT 26 |
| NOVEMBER | NOV 16 | NOV 16 | NOV 16 | NOV 16 |
| DECEMBER | DEC 14 | DEC 14 | DEC 14 | DEC 14 |

[Click here to view the conference schedule](#) – Check the conference bag received when you check in for revisions. The Registration Room will open at 1 pm on Wednesday – please register immediately upon arrival.



Friday afternoon Clinics will be held at the University of Michigan's [C.S. Mott Children's Hospital](#), 1500 E.

Medical Center Drive in Ann Arbor.

The clinics are listed below. [Click here to review the Conference Schedule](#), which includes bus loading times.

- Otolaryngology
- Infectious Disease
- GI
- Ortho

- Immuno-
Hematology
- Genetics

- Pulmonology

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Workshops will be held Thursday, July 19 and include these. [See the Schedule](#) for more information and refer to your “conference bag” handouts for any updates.:

- 1a Cardiac Surgery, Dr James Hammel
- 1b Self Care
- 1c Wheelchair and Seating
- 1d Simon’s Law

- 2a The TRIS Project, Debbie Bruns, PhD
- 2b Canvas Painting Party or Cardmaking
- 2c Wheelchair and Seating

- 3a Genetics, Dr John Carey
- 3b Light Sensitivity, Seizures, Headaches, Dr Steve Cantrell
- 3c Wheelchair and Seating
- 3d “I am the

journey” –

Martina

Biagi

▪ 4a Mom’s

Only –

Sharing

Workshop

▪ 4b Dad’s

Only –

Sharing

Workshop

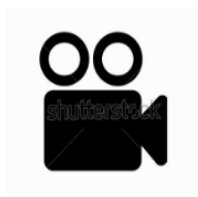


The **Welcome Dinner** will be held Thursday night and the Keynote Speaker will be Dr Glenn Green of C.S. Mott Children’s Hospital. Dr Green specializes in pediatric otolaryngology and his area of practice includes complex pediatric airway, hearing and language development, and

care of the child with a congenital syndrome.

In addition to Dr Green's talk, the dinner will include the "**SOFT Friends**" video, the **Erin Jorgenson scholarship award**, entertainment, plenty of opportunity to socialize with families and friends!.

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SOFT's Annual "SOFT Friends" video, in memory of Kari Holladay, will be shown at the Welcome Dinner Thursday night.

[Here is a link to a page](#) that explains the video and how to submit photos to Kari's mom, Kris. ***Emailed photos must be sent to Kris by June 1st. If mailed, they must arrive by June 7.***



The annual SOFT Remembrance Outing will be held at the University of Michigan's [Matthael Botanical Gardens](#) on Friday afternoon – see schedule for times..



The Older Siblings Outing will be to the Detroit City Zoo. The cost is \$42 which includes transportation, a T-shirt and Lunch. See the schedule for loading and return times.



The Memory Room will be will be open as outlined in the conference schedule. Please bring photo albums or other memorabilia to display! Be sure to remove your belongings prior to closure!.



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The Saturday picnic will be held at [Dawn Farms in Ypsilanti](#). See the Schedule for times.



The annual [SOFT Balloon Celebration](#) will be held at the Saturday Picnic. Use the registration form to request a balloon release. Conference attendees may also request one on a “walk-in” basis, at the picnic.



The Auction will be held Saturday night and details will be posted here when they are known. Please send your Auction Donation Items to Kayse Whitaker at 619 William St, Kalamazoo, MI 49007



On Thursday, child care will be provided as detailed in the schedule – please refer to that for times and places.

The [Joey Watson Memorial Conference Attendance Assistance fund](#) exists to help needing and qualifying families who require transportation and registration assistance to attend the conference. The deadline for submitting the form is May 15th and requestors must seek other assistance in their communities prior to asking for help from this fund. These funds are very limited, so start early. Click the blue link to open the form.



[Transportation Security Administration \(TSA\) Travel Tips](#), for those traveling by air with children and/or equipment.

