I have attended four FIRST National conferences, with my parents in the ‘90s and now my own family. Each time I learn something new, make new friends, and leave the conference bursting with hope for the future of our rare disease. If you or a family member is affected with ichthyosis or a related skin type, this is an absolute “don’t miss” event. Here’s why…

Meet the Medical Experts - The National Conference offers the rare opportunity to learn from ichthyosis & related skin type experts. Experts. One-on-one clinical appointments available.

Surround Yourself with Affected Families & Individuals - For once, ichthyosis is the majority. You’ll see people with your type of ichthyosis everywhere. Through casual encounters, formal presentations, and in-depth conversations, you will feel it and see it: you are not alone. This, by itself, is a life-changing experience.

**Program** (subject to change)

**Thursday, June 23**
7 - 8 pm ....................... Early Bird Registration
7 - 10 pm ........................... Evening Social

**Friday, June 24**
7 - 8:30 am .......... Breakfast & Registration
9 - 10:30 am ............. Conference Kick-Off
10:30 - 12 ................. Research Panel
12 - 1:00 pm ............... Lunch
1:15 - 2:15 pm ............ Types of Ichthyosis
2:30 - 4:15 pm ............. Sessions
6 pm ............................ Pizza & Trolley Tour (optional)

**Saturday, June 25**
7:30 - 8 am............. Light Yoga Stretch (optional)
8 - 9:30 am ....................... Breakfast
8 - 5:00 pm .......... Clinical Screening & Registry
9:30 - 10:30 am ............ Keynote Speaker
10:45 - 12:00 pm ....... Panel Discussions
12:00 - 1:00 pm ............ Lunch
1:15 - 3:00 pm ............ Panels & Sessions
3:15 - 5:00 pm ........... Support Groups
6:30 - 10:00 pm Beach Party & Dinner Dance

**Sunday, June 26**
7:30 - 8 am............. Light Yoga Stretch (optional)
8 - 9:30 am ........................ Breakfast
9:45 - 11:45 am .................. Breakouts
12:00 - 12:30 pm .......... Conference Wrap-Up
12:30 - 2 pm ................... Farewell Lunch

**Kid-a-Palooza**
A supervised kid’s camp for ages one to completed fifth grade will be offered concurrently with all educational sessions for little ones to play, laugh, and have fun while parents attend lectures and breakouts. Your child(ren) will re-join you for all meal functions. A licensed childcare company will be hired. A nominal fee is required so FIRST can confirm how many are planning to use this service and the appropriate number of childcare providers are hired for your child’s safety.

**Tween & Teens**
Interactive and educational breakouts. Plenty of opportunities to attend general sessions, hangout time, enjoy the pool together, plus more!

**Make Friends that Last a Lifetime** - Many parents feel overwhelmed with everything that comes along with an ichthyosis diagnosis, and the “ichthyosis family” is a support network that runs far and wide. You will no doubt spark connections for a lifetime.

**Get ideas** - Did you know that some people use a Dremel drill for their feet? That sleeping with surgical gloves can help your cream work? Some of the most effective treatments I’ve found have been from suggestions at the conference.

**Stay In-the-Know** – You’ll hear all the latest in research, from the scientists themselves! You’ll learn what’s new with FIRST, and how to get involved.

**See Your Future** – New parents with affected toddlers can meet happy and adjusted teens with ichthyosis. Young adults can talk with 30-somethings and adults can visit with seniors to find out what issues and solutions they’ve found for aging with ichthyosis.

**Inspire Others** - I’ll never forget how strong I felt when I lifted up a room full of parents just by sharing my own story. Your strength will empower you and inspire others.

**Have fun!** - From dawn till dusk, and beyond, the positive energy of the conference is contagious. Plus it all wraps up with a Saturday night dance party and talent show!

**Meet the FIRST staff** - Did you know Jean Pickford has been with FIRST for more than 15 years? Meet all our staff members who are committed to the mission of FIRST! You’ll have a chance to get encourage them in the work they’re doing.

**Score Free Samples** - Generous sponsors and companies that are working on products just for ichthyosis contribute massive amounts of freebies. The “swag bag” is VIP all the way.
Making Hotel Room Reservations

FIRST’s discounted group rate at the Marriott Mission Valley is $189* per night, from June 23 through June 25. The discounted guestroom internet fee is $6 per day. Self parking is $12 per day. All attendees must make their own hotel reservations in one of two ways:

1. **Online Reservations** - A dedicated booking website has been created just for our conference to make, modify and cancel their hotel reservations online at this link: https://resweb.passkey.com/go/FIRSTOverflow2016

   *The hotel is still honoring the shoulder dates of June 19 to June 22 and June 26 to June 29 at the $129++ room rate until those room blocks fill. When making your reservations including any of those dates, the discounted rate of $129 will be modified by the group sales manager internally and will be reflected on your final bill. The dates of Thursday, June 23 – Saturday, June 25 will be billed at $189++.*

2. **Phone** - Please use the following numbers to make your reservation by phone. When making your reservation, be sure to reference the “Foundation for Ichthyosis” to book within our group room block and receive the discounted rate. Reservations toll free: 877-622-3056 or reservations local phone: 619-692-3800.

   For general questions about the hotel, driving directions, amenities, etc., contact the hotel directly at 619.692.380 or visit their website at http://www.marriott.com/hotels/travel/sanmv-san-diego-marriott-mission-valley/.

Airport & Shuttle Information

San Diego International Airport (SAN) is the major airport for the San Diego area and is about eight miles from the hotel. You may be eligible for free transportation using the Air Charity Network. To find out if you are eligible for free transportation to and from the conference, please contact Air Charity Network directly at 877.621.7177.

There are several travel options between the airport and hotel:

- Supershuttle: 1(800)BLU-EVAN — supershuttle.com $12.00 per person to/from airport
- Yellow Cab: (619)444-4444 — sandiego.driveu.com/taxi.php $25—$30 per cab one way (fits up to 4 persons)
- Town Car/Limo Service: SanLimo Transportation (858)752-7291 — sanlimo.com — san.limo@yahoo.com Contact: Harry Sharifi — $28 flat rate one way (up to 4 persons)
- Uber: Available to pick up and drop off to/from the airport for around $19—$25. Contact the hotel for discount codes up to $20 off for those who have never used Uber before.

Friday Pizza & Trolley Tour (Optional)

This optional activity features a casual pizza get-together at the hotel before embarking on a two-hour trolley tour of beautiful San Diego. Sights include Old Town, San Diego Harbor and Embarcadero, Seaport Village, Horton Plaza, Historic Gaslamp Quarter, Coronado, Balboa Park and Little Italy. All trolleys will stop midway through the tour at Coronado Beach for a bathroom break and leg stretch. Sign-up on the registration form to reserve your spot(s).

Dress Code, Meals, Attractions

The conference attire is casual. Your registration fee includes Friday breakfast & lunch, Saturday breakfast, lunch & dinner, and Sunday breakfast & lunch. The San Diego Marriott Mission Valley provides easy access to popular attractions including Old Town, Mission Bay, the Rio Vista Trolley, SeaWorld® San Diego, Qualcomm Stadium, home of the San Diego Chargers, and Petco Park, home of the San Diego Padres. For more information on area attractions, go to www.sandiego.org/plan-your-trip/travel-guides or access special offers and coupons by visiting www.sandiego.org/coupons.

FIRST’s Got Talent (Optional)

Back for its fifth conference! This is a popular and heartwarming experience for kids, ages 5—17, to showcase their talents. Performances are on Saturday evening after dinner. Speakers and microphone will be provided; bring your own music, costume, props, etc. Performances will be limited to a max of two minutes. Sign-up on the registration form.

Stay Tuned In... #FIRSTNC16
**Family Registration, Contact Info, and Permissions**

Family Last Name: __________________________ Contact Person: __________________________

Address: ___________________________________________________________________________

City/Town: __________________________ State/Province: _____ Zip/Postal Code: __________

Country: ____________________________ Home Phone: ____________________________

Cell: _______________________________ Email: ________________________________

Type of Ichthyosis: ___________________________________________________________________

☒ I give FIRST permission to publish names, contact, and type of ichthyosis in the conference roster, which will be distributed to attendees, vendors & faculty attending the event.

☒ I give FIRST permission to use and distribute any photos or videos taken at the conference, in which I, or my family, may be a part, including but not limited to use in newsletters, appeals, social media, website and reports.

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**Who’s Attending?**

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<th>Date of Birth</th>
<th>Age</th>
<th>Affected with Ichthyosis or a related skin type?</th>
<th>Relationship to person affected? (mom, brother, uncle, friend, etc.)</th>
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**Clinical Appointments & Yale Registry**

All appointments will be scheduled for Saturday, June 25

This unique opportunity is offered to any affected member(s) and families to meet with expert dermatologists and researchers from Yale University. Please check which option you are interested in:

- **Option 1**—A 15 minute appointment with experts in ichthyosis to discuss your/your child diagnosis. This option does not involve participation in any research studies.

- **Option 2**—A more in-depth, longer appointment to enroll in the Yale Registry for research studies. This option also includes a 15 minute appointment with expert dermatologists as well. For new enrollees, the study will involve providing a saliva sample, photographs, and completing a questionnaire.

- **Option 3**—For those already enrolled in the Yale Registry, you are encouraged to still sign up, as there will be an opportunity to update information, ask any questions, and participate in continued Registry activities.

**Registration & Payment**

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<td>Infant/Toddler</td>
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**Optional Add-Ons**

- **Kid-a-Palooza** (ages 1 to completed fifth grade) x $10 per child = $

**Friday Night Pizza & Trolley Tour**

- Adult: Ages 13+ x $35 per person = $
- Child: Ages 4 to 12 x $21 per person = $
- Toddler: Ages 3 and under x $3 per person = $

**Celebrate FIRST’s 35th anniversary with a $35 gift to support the Conference Scholarship Fund—helping those who need it most…** $

**Grand Total** $

- Enclosed is a check in the amount of $______________, payable to FIRST, Inc.
- Please charge my credit card for $______________(Visa, Mastercard, American Express, Discover)

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**Waiver**

In consideration of the acceptance of this registration entry, I/we the undersigned, assume full responsibility for any injury or accident which may occur while I/we am/are attending this conference. I/we hereby release and hold harmless the sponsors, promoters, and all other persons and entities associated with this event from any and all personal injury or damage, whether it be caused by the negligence of the sponsors, promoters or other persons or entity. Applications for minors will be accepted only if signed by a parent or guardian.

**Signature**

**Date**

**See You In San Diego!**