



2014 National Family Conference Program

June 20 - 22
Hilton Indianapolis



Thursday, June 19

Clinical Screening & Genetic Studies	All	3 - 9 pm	Clinical Screenings (Option 1) Clinical & Research Visits (Option 2) Pre-Scheduled Appointments	All Patients Report to Circle City 3 (Third Floor) for Check-in at your Appointment Time	All Physicians
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Friday, June 20

Registration	All	7 - 8:45 am	It's Finally Here! <i>Check in to receive your sample bag, t-shirt, and other conference information</i>	Monument Foyer & Monument Hall Lower Level	All
Breakfast	All	7 - 8:45 am	Breakfast	Monument Hall - Lower Level	All
Clinical Screening & Genetic Studies	All	7 - 10 am	Clinical Screenings (Option 1) Clinical & Research Visits (Option 2) Pre-Scheduled Appointments	All Patients Report to Circle City 3 (Third Floor) for Check-in at your Appointment Time	All Physicians
Fun & Games	Children Ages 1 - 12	8:30 - 9:00 am	Kid's Camp Registration <i>Parents of registered children must complete the necessary paperwork to ensure the safety of your child</i>	Circle City 4th Floor (Ages 1 - 4) Circle City 6th Floor (Ages 5 - 8) Circle City 7th Floor (Ages 9 - 12)	Corporate Kids Events
		8:30 - 12 pm	Kid's Camp <i>Children will have a fun, entertaining, and safe experience! All participants must be pre-registered</i>	Circle City 4th Floor (Ages 1 - 4) Circle City 6th Floor (Ages 5 - 8) Circle City 7th Floor (Ages 9 - 12)	
Opening Session	Adults & Teens	9:00 - 9:15 am	It's Time To Educate, Inspire & Connect <i>Hear from FIRST's President about what to expect from this unique weekend experience</i>	Monument Hall - Lower Level	Mike Briggs FIRST President
Keynote Address	Adults & Teens	9:15 - 10:15 am	Rick Guidotti <i>Different is Beautiful</i>	Monument Hall - Lower Level	Rick Guidotti

Friday, June 20

Let's Get Focused! Breakouts On Specific Types	Adults	These breakouts will feature a medical lecture given by knowledgeable dermatologists followed by audience question & answer.			
		10:30 - 12 pm	Autosomal Recessive Congenital Ichthyoses - ARCI <i>(Lamellar, CIE, Harlequin, Collodion)</i>	Indianapolis Ballroom - 2nd Floor	Drs. Britt Craiglow, Jon Dyer, Moise Levy & Erin Mathes
			Epidermolytic Ichthyosis (EI)	Victory Ballroom - 9th Floor	Drs. Keith Choate & Anne Lucky
			Netherton & Related Skin Types	Corydon Room - 2nd Floor	Drs. Susan Bayliss & Amy Paller
			X-linked Ichthyosis / Vulgaris	Vincennes Room - 2nd Floor	Drs. Philip Fleckman, Jennifer Hand & Robert Silverman
	Syndromes & Ultra-Rare Ichthyoses	Circle City 10th Floor	Drs. Leonard Milstone & William Rizzo		
	Teens Only	10:45 - 12 pm	We're Glad You're Here! <i>Exclusively for teens to meet each other and hang out with Rick Guidotti</i>	Circle City 8th Floor	Moureen Wenik & Rick Guidotti
Lunch	All	12 - 1 pm	Lunch & Trivia <i>Connect with new friends and play FIRST Trivia!</i>	Monument Hall - Lower Level	All
Fun & Games	Children Ages 1 - 12	1 - 4:30 pm	Kid's Camp <i>Children will have a fun, entertaining, and safe experience! All participants must be pre-registered. From 2:45 - 3:45 pm, affected children will have an opportunity to chat with several teens, in a small group session, about living with ichthyosis</i>	Circle City 4th Floor (Ages 1 - 4) Circle City 6th Floor (Ages 5 - 8) Circle City 7th Floor (Ages 9 - 12)	Corporate Kids Events
Ichthyosis & Beyond Other Issues Beyond Your Skin	Adults	These breakouts will feature a medical lecture given by knowledgeable dermatologists followed by audience question & answer.			
		1 - 2:30 pm	Your Skin: Inside & Out <i>Learn how to manage infections, understand the long-term use of antibiotics and retinoids, and tips to control itch</i>	Indianapolis Ballroom - 2nd Floor	Drs. Leonard Milstone, Amy Paller & Robert Silverman
			A Whole New World <i>Overwhelmed? Newly diagnosed families learn how to manage ichthyosis and calm your biggest fears</i>	Vincennes Room - 2nd Floor	Drs. Britt Craiglow & Anne Lucky
		Genetics 101 <i>A lesson about genetics and its effects on your family</i>	Corydon Room - 2nd Floor	Drs. Keith Choate & Fernando Escobar	
	Teens Only	1 - 2:30 pm	Gather Around the Table <i>Teens will separate into two groups of affected and unaffected siblings for group discussion</i>	Circle City 8th Floor	Moureen Wenik
Cookie Break	All	2:30 - 2:45 pm	Break <i>Nothing like a cold drink or a cookie to perk you up!</i>	2nd Floor Foyer	All

Friday, June 20

Ask the Experts	Adults & Teens	2:45 - 3:45 pm	Pediatric Panel <i>Bring any and all of your questions to ask the medical experts about pediatric concerns</i>	Indianapolis Ballroom - 2nd Floor	Drs. Susan Bayliss, Heather Brandling-Bennett, Jon Dyer, Moise Levy, Anne Lucky, Amy Nopper & William Rizzo
			Adult Panel <i>Bring any and all of your questions to ask the medical experts about adult concerns</i>	Victory Ballroom - 9th Floor	Drs. Keith Choate, Philip Fleckman, Leonard Milstone & Robert Silverman
If Not You, Then Who?	Adults & Teens	3:45 - 4:30 pm	FUN - Raising Mocktail Party <i>Learn from others who have successfully hosted big and small Fundraisers. <u>U</u>nite together to explore your own ideas. <u>N</u>ow is the time to take the first step!</i>	Indianapolis Ballroom - 2nd Floor	Cossel, Klafter, Kocher & Robinson Families
On Your Own	All	4:30 pm	Enjoy Yourselves <i>In beautiful downtown Indianapolis...see you in the morning!</i>	Visit http://visitindy.com/fnfc14	All
Regional Support Network	Volunteers	4:30 - 5:30 pm	Want to make a difference in other's lives? <i>Attend this meeting and learn what area of volunteerism in the Regional Support Network is a good fit for you</i>	Victory Ballroom - 9th Floor	All current & prospective RSN members

Saturday, June 21

FIRST Board Meeting	Board & Staff	7 - 8:00 am	Board of Directors Semi-Annual Meeting	Circle City 14th Floor	Board Members, Emeriti & Staff
Breakfast	All	7 - 8:45 am	Breakfast	Monument Hall - Lower Level	All
Fun & Games	Children Ages 1 - 12	8:30 - 12:30 pm	Kid's Camp <i>Children will have a fun, entertaining, and safe experience! All participants must be pre-registered</i>	Circle City 4th Floor (Ages 1 - 4) Circle City 6th Floor (Ages 5 - 8) Circle City 7th Floor (Ages 9 - 12)	Corporate Kids Events
Research Progress To Find A Cure	Adults & Teens	9 - 10:30 am	What's Up with Research? <i>A lecture series from leading investigators about current research discoveries followed by Q & A from the audience</i>	Monument Hall - Lower Level	Drs. Keith Choate, Philip Fleckman, Leonard Milstone, Amy Paller, and William Rizzo

Saturday, June 21

These breakouts will be lead by a volunteer physician and/or professional moderator and will be an open discussion format.					
Up, Down & All Around	Adults	10:45 - 11:30 am	Head to Toe <i>Share and learn different management techniques for scalp, hair, and foot care</i>	Indianapolis Ballroom - 2nd Floor	Dr. Leslie Costelo-Soccio
			It's Getting Hot in Here <i>Share and learn different management techniques for sweating and overheating</i>	Victory Ballroom - 9th Floor	Drs. Moise Levy & William Rizzo
			Stop, Look & Listen <i>Share and learn different management techniques for eyes and ears</i>	Corydon Room - 2nd Floor	Dr. David Bryson & Shannon Hamill
Hanging Out	Teens Only	10:45 - 11:30 am	Let's Get Real <i>Honest and realistic conversations with young adults who've been there, done that</i>	Circle City 8th Floor	Bailey Pretak
These breakouts will be lead by a volunteer physician and/or professional moderator and will be an open discussion format.					
Up, Down & All Around II	Adults	11:45 - 12:30 pm	Head to Toe <i>Share and learn different management techniques for scalp, hair, and foot care</i>	Indianapolis Ballroom - 2nd Floor	Dr. Leslie Castelo-Soccio
			It's Getting Hot in Here <i>Share and learn different management techniques for sweating and overheating</i>	Victory Ballroom - 9th Floor	Drs. Moise Levy & William Rizzo
			Stop, Look & Listen <i>Share and learn different management techniques for eyes and ears</i>	Corydon Room - 2nd Floor	Dr. David Bryson & Shannon Hamill
Can You Relate?	Teens Only	11:45 - 12:30 pm	Relationships, Dating, and More <i>Moderated discussion about healthy relationships, dating, and how to respect yourself and others</i>	Circle City 8th Floor	Dr. Bethanee Schlosser
Lunch	All	12:30 - 1:30 pm	Lunch & Awards	Monument Hall - Lower Level	All
Fun & Games	Children Ages 1 - 12	1:15 - 5:15 pm	Kid's Camp <i>Children will have a fun, entertaining, and safe experience! All participants must be pre-registered</i>	Circle City 4th Floor (Ages 1 - 4) Circle City 6th Floor (Ages 5 - 8) Circle City 7th Floor (Ages 9 - 12)	Corporate Kids Events
We are Outta' Here	Teens Only	1:30 - 5:00 pm	Teen Field Trip <i>Chaperoned teens spend the afternoon hanging out at the mall; Pre-registration is required</i>	Circle Centre Mall	Corporate Kids Events

Saturday, June 21

Body Beautiful	Adults	1:30 - 2:45 pm	Everything But The Kitchen Sink <i>Open discussion with each other about skin care products & techniques</i>	Indianapolis Ballroom - 2nd Floor	Lisa Kass & Sam Zavitz
			Soak and Scrub: Ichthyosis & The Tub <i>Open discussion with each other about the bathing process, additives, and bathtime habits</i>	Victory Ballroom - 9th Floor	Jolie & Sean Cina
			Stressed Out? <i>Natural approach for wellness, balance, and healthy living</i>	Corydon Room - 2nd Floor	Dr. Vindhya Veerula
			Unique considerations for women with ichthyosis <i>Identifying and addressing the unmet needs of women as it relates to your overall skin health, sexual functioning, and quality of life</i>	Vincennes Room - 2nd Floor	Dr. Bethanee Schlosser
Snack Break	All	2:45 - 3:15 pm	Afternoon Refresher <i>Enjoy a pick-me-up snack!</i>	2nd Floor Foyer	All
You Are Not Alone Support is Just One Person Away	Adults	These breakouts will be lead by a volunteer moderator and will be an open discussion format. Here's your opportunity to connect with others who "get it."			
		3:15 - 5:15 pm	Mom's Group I	Indianapolis Ballroom - 2nd Floor	Sarah Hodgkinson & Kelly Klafter
			Mom's Group II	Victory Ballroom - 9th Floor	Denise Benedetto & Sarah Kimmelman
			Dad's Group	Corydon Room - 2nd Floor	Mark Steinitz
			Young Adult's (YAWI) Group	Circle City 10th Floor	Dhiren Patel
			Women's Group	Vincennes Room - 2nd Floor	Jackie Barrett & Beth Hampshire
			Men's Group	Private Area in 120 West Restaurant - 1st Floor	Tim Ohlwiler
			Grandparent's Group	Private Area in 120 West Restaurant - 1st Floor	Mary & Dave Cina
Spouse's Group	Private Area in 120 West Restaurant - 1st Floor	Tom Clemmer			
Party Time!	All	6:30 - 10:30 pm	Dinner, Dancing & Entertainment <i>We've got it all! Sit back, relax, eat, unwind, drink, dance, sing, and enjoy our very own entertainers & photo booth</i>	Monument Hall Lower Level	

Sunday, June 22

Breakfast	All	7 - 8:45 am	Breakfast	Monument Hall - Lower Level	All
Fun & Games	Children Ages 1 - 12	8:45 - 12:30 pm	Kid's Camp <i>Children will have a fun, entertaining, and safe experience! All participants must be pre-registered</i>	Circle City 4th Floor (Ages 1 - 4) Circle City 6th Floor (Ages 5 - 8) Circle City 7th Floor (Ages 9 - 12)	Corporate Kids Events
Stand Up, Stand Out I	Adults & Teens	9 - 9:45 am	The Future's So Bright, I Gotta' Wear Shades Panel of teens/young adults will share ups-and-downs and answer questions from parents of younger children about what to expect	Indianapolis Ballroom - 2nd Floor	Moureen Wenik
			How Rude! Can You Believe They Said That? <i>How to the turn negative feelings into a positive; learn and share tips for addressing rude people</i>	Victory Ballroom - 9th Floor	Dr. Eric Scott
			It's Elementary, Dear Watson <i>Prepare for the school year - learn from other parents about everything school-related, from IEPs to bullying to classroom accommodations</i>	Vincennes Room - 2nd Floor	Suzanne Dunkin
			Could it happen to me? <i>Learn ways for students/parents to confront bullying behavior and build self-esteem. Members of the BDU "No Bully Crew" will share testimonies about bullying behavior and ways to stand-up to it.</i>	Corydon Room - 2nd Floor	Flora M. Jones
Stand Up, Stand Out II	Adults & Teens	10:00 - 10:45 am	The Future's So Bright, I Gotta' Wear Shades Panel of teens/young adults will share ups-and-downs and answer questions from parents of younger children about what to expect as they get older	Indianapolis Ballroom - 2nd Floor	Moureen Wenik
			How Rude! Can You Believe They Said That? <i>How to the turn negative feelings into a positive; learn and share tips for addressing rude people</i>	Victory Ballroom - 9th Floor	Dr. Eric Scott
			Fifty Is The New Twenty - Aging with Ichthyosis <i>You're never too old to learn about changes and caring for your skin as you age</i>	Vincennes Room - 2nd Floor	Ellen Clemmer
			Could it happen to me? <i>Learn ways for students/parents to confront bullying behavior and build self-esteem. Members of the BDU "No Bully Crew" will share testimonies about bullying behavior and ways to stand-up to it.</i>	Corydon Room - 2nd Floor	Flora M. Jones

Sunday, June 22

Best Foot Forward	Adults	11 - 11:45 am	Hey Doc, Can You Repeat That? <i>Tips for getting the most from your doctor's visits so you don't leave with more questions</i>	Indianapolis Ballroom - 2nd Floor	Dr. Phil Fleckman
			#Powerofsocialmedia <i>Panel of bloggers, tweeters, and facebook friends sharing how to use social media for support</i>	Victory Ballroom - 9th Floor	Kimberly Cole, Courtney Westlake, and Jennifer See
			Don't Be Shy! <i>Feeling motivated? Meet with our Development Coordinator to share your enthusiasm and energy for a possible future fundraiser</i>	Vincennes Room - 2nd Floor	Chris Wassel
			S'more Fun <i>Learn from former summer campers about what camps are available for children and teens with skin disorders</i>	Corydon Room - 2nd Floor	Drs. Britt Craiglow & Meena Julapalli, Linda Balog & Hunter Steinitz
Stay Connected	Teens Only	11 - 11:45 am	Talk To Ya' Later <i>Closing session for teens to say their goodbyes and share their contact info to stay in touch</i>	Circle City 8th Floor	Moureen Wenik
Farewell & Lunch	All	12:00 - 1:30 pm	Closing - 'Til we meet again! <i>You came, you were educated, you were inspired, and you connected. See you in 2016!</i>	Monument Hall - Lower Level	All

