

New Jersey Leadership Education in Neurodevelopmental Disabilities ~ NJLEND

Presents:



TWICE BORN: *How one family experienced the life altering event of fetal surgery and its outcome while taking part in an Emmy-winning PBS documentary series, and learned about the power of love and the intricacies of navigating the healthcare system along the way.*

This unique talk and film showing sheds light on the complex relationships between healthcare professionals and parents in the face of circumstances that change all the assumptions of everyday life. In 2013 at age 23, Lesly Leiva learned that the baby she was expecting had a life-threatening oral tumor. On her own she made a decision to go to Children's Hospital of Philadelphia where CHOP's fetal surgery unit offered her the option to deliver the baby via EXIT procedure; this would allow surgeons to operate on the tumor while the baby was still partially in the womb. Lesly's experience, and the following 15 months in her child's life became a central story in a PBS series about the fetal surgery unit. In the intervening four years, Lesly has seen her child through multiple additional surgeries and healthcare crises, and has also become a healthcare professional herself.

Monica Lange, the producer/director and executive producer, will present portions of this documentary film. Lesly Leiva, mother of Lilly now age 4, will reflect on the dual experiences of being a parent of a child with ongoing health needs, and becoming a nurse who brings her own perspective to the provider's role in delivering to families what they really need.

Date: Friday, March 2, 2018

Time: 9:30 AM to 12:30 PM
Registration will begin at 9:00 AM. Coffee and tea will be provided.

Location: Children's Specialized Hospital Auditorium
200 Somerset Street, New Brunswick, NJ 08901

Speakers: Keynote by Monica Lange, Emmy Award winning Director of PBS Documentary "TWICE BORN" with Special Guest Lesly Leiva

Registration: *There is no charge for this program but space is limited and registration is required.*
Register online at: <http://rwjms.rutgers.edu/boggscenter/student/NJLEND1.php>

Speaker Biographies

Monica Lange



Monica Lange is a television producer and filmmaker with 25 years of experience and multiple awards. She recently produced, directed, and executive produced “TWICE BORN: Stories From The Special Delivery Unit,” a PBS mini-series and winner of the 2016 Emmy for Outstanding Science and Technology Programming and the Jackson Hole Science Media Award.

From 2007 to 2013 Monica produced, directed, and wrote documentaries and reality mini-series for Discovery Communications. Her hour “Unlocking Autism” documentary, about research into the causes of the disability, won The Academy of Television Arts and Sciences esteemed Academy Honors for “Television With a Conscience.” Among her Discovery credits are: “Autism x6,” about a family with six children on the spectrum; a special about the realities of multiple births; an hour about the psychological and physical consequences of the separation of conjoined twins; and another about the life of a child with Prader Willi Syndrome. Her eight part series, “Sextuplets Take New York” about the first Hispanic sextuplets in the US was praised in The New York Times for its portrayal of the immigrant experience.

“TWICE BORN: Stories From The Special Delivery Unit” can be found on Amazon Prime at: <https://www.amazon.com/ Twice-Born-Stories-Special-Delivery/dp/B00TZF2O7I> and on the PBS website at: <http://www.pbs.org/program/twice-born/>

Lesly Leiva



Lesly Leiva is the mother of Lilly, a spunky little four year old girl. In 2013, Lilly was born via “EXIT procedure” at The Children’s Hospital of Philadelphia in order to save her life. Lesly has faced a hard road with Lilly, and feels blessed every day to be able to watch her grow smarter and wiser. Lilly is Lesly’s inspiration to continue to be strong and to never give up. As Lesly has watched Lilly face her struggles in life, it continues to remind her that Lilly needs her more than ever, so Lesly continues to better herself in all ways possible and continues to look for ways to help her daughter as much as she can.

Lesly and Lilly currently live in Lakehurst, New Jersey. Lesly attends Georgian Court University, where she will graduate with her Bachelors of Science in Nursing, May 2018.

As for her future goals, Lesly plans to further her education by getting her Doctor of Nursing Practice degree (DNP). Lesly also wants to continue to reach out to other parents who may be encountering similar situations and to encourage them to never lose hope.

Directions and Parking

Children's Specialized Hospital Auditorium

200 Somerset Street

New Brunswick, NJ 08901

From The North (I-95 South / New Jersey Turnpike Cars Only Lane South):

At Exit 9, take ramp right for RT-18 North toward Tower Center Blvd. / New Brunswick / Trenton / Princeton for 0.9 miles. Bear right onto SR-18 North for 2.2 miles. Take ramp right for SR-27 South / Albany St. toward Princeton for 0.5 miles. Turn right onto CR-527 / Easton Ave and travel 0.1 miles. Turn left onto Somerset St. and travel 0.3 miles. Children's Specialized Hospital is on left side at the corner of Somerset and Plum Streets. To access the parking garage from Somerset St., continue on Somerset St. past Plum St. and turn left onto Prospect St. At the end of Prospect St., turn left onto French St. and make a quick left onto Plum St. The entrance to the parking garage is on the left.

From The South (I-95 North / New Jersey Turnpike North):

At Exit 9, take ramp right for RT-18 North toward Tower Center Blvd. / New Brunswick / Trenton / Princeton for 0.9 miles. Bear right onto SR-18 North for 2.2 miles. Take ramp right for SR-27 South / Albany St. toward Princeton for 0.5 miles. Turn right onto CR-527 / Easton Ave. and travel 0.1 miles. Turn left onto Somerset St. and travel 0.3 miles. Children's Specialized Hospital is on left side at the corner of Somerset and Plum Streets. To access the parking garage from Somerset St., continue on Somerset St. past Plum St. and turn left onto Prospect St. At the end of Prospect St., turn left onto French St. and make a quick left onto Plum St. The entrance to the parking garage is on the left.



Walking Directions from the Plum Street Parking Deck:

From the Plum Street parking deck, take the bridge from the 2nd level of the parking garage to the hospital, walk up the ramp with the purple walls, passing under the PSE&G Children's Hospital sign, and follow the signs to the Children's Specialized Hospital lobby. It will be around to the left.

Once you arrive at the CSH lobby, take either the stairs or the elevator down to the ground floor, where you will register and sign-in in the foyer of the auditorium. You will also need to sign-out when you leave.

Hold These Dates: NJLEND Continuing Education Spring 2018

Developmental Disabilities Lecture Series

- Topic:** Autism
- Speaker:** Cathy Pratt, PhD, BCBA-D
Director, Indiana Resource Center for Autism, Indiana University
- Date:** Thursday, April 12, 2018
- Time:** 9:30 AM to 12:30 PM
- Location:** APA Hotel Woodbridge
120 Wood Avenue South, Iselin, NJ 08830
- Registration:** There is no charge for this program but registration is required and space is limited. Registration will open in mid-February. Register online at:
http://rwjms.rutgers.edu/boggscenter/dd_lecture/sessions.html

NJLEND 2018 Maternal and Child Health Leadership Symposium

- Topic:** Epigenetics
- Speaker:** Keynote by Daniel A. Notterman, MD
Professor of Molecular Biology, Princeton University
- Date:** Friday, May 11, 2018
- Time:** 9:00 AM to 12:00 PM
- Location:** Children's Specialized Hospital Auditorium
200 Somerset Street, New Brunswick, NJ 08901
- Registration:** There is no charge for this program but registration is required and space is limited. Registration information will be provided at a later date.

NJLEND is a designation of the Maternal and Child Health Bureau, Health Resources and Services Administration (Grant # T73MC30120)

RUTGERS

Robert Wood Johnson
Medical School

The Boggs Center on Developmental Disabilities
Department of Pediatrics
Rutgers, The State University of New Jersey
Liberty Plaza, 335 George Street
New Brunswick, NJ 08901

rwjms.rutgers.edu/boggscenter
p. 732-235-9300
f. 732-235-9330