

ALD NBS Family Retreat

@ The Painted Turtle

Friday, October 4th

- 1 – 2:30 PM Participant Check In
Settle into housing
- 3:00 PM Introduction and Welcome
Overview of ALD as a Disease and a Community (Nic Adler)
- 3:30 PM Family Introductions (TPT Staff)
Family Meet and Greet
Ice breakers and introductory game
Introduction and welcome to The Painted Turtle
- 4:30 PM Parents: Adrenal Insufficiency in ALD: Etiology, natural history, and management (Sejal Shah)
- Children and Caregivers:
Infant Play Area, arts and crafts, woodshop
- 5:30 PM Break
- 6:00 PM Dinner
- 7:00 PM Opening Campfire (TPT Staff)
- 8:30 PM Settle into Cabins/Cabin Time
Settle into cabins for the weekend
Meet other participants in your cabin



Saturday, October 5th

- 7:30 AM Morning Activities (Optional)
Infant play area, fishing, woodshop
- 8:30 AM Breakfast
- 9:30 – 12:30 Children and Caregivers:
Infant play area, woodshop, arts and crafts, animal adventures,
open gym, pool (weather permitting)
- 9:30 AM Parents: Neurologic health in ALD: expectations and outcomes in the era
of newborn screening (Dr. Keith Van Haren)
- 10:30 AM Parents: Advanced Therapies in ALD: stem cell transplant and gene
therapy (Ami Shah)
- 11:30 AM Parents: Camp activities with children/caregivers
- 12:30 PM Lunch
- 1:30 PM Chill Time
Rest time – activity areas are closed at this time
- 3:00 – 6:00 Children and Caregivers:
Infant play area, woodshop, arts and crafts, fishing, open gym,
archery (age permitting)
- 3:00 PM Parents: Breakout Sessions
- Diet Basics: Meet with a Chef and Dietician
 - Alternative Therapies
 - Additional ways to support: Advocacy and Fundraising
- 4:30 PM Parents: Cooking Class
- 5:15 PM Parents: Join Camp Activities with children/caregivers

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6:00 PM Dinner

7:00 PM All Camp: Stage Night

8:15 PM Parents: Parent Café
Children and Caregivers: Cabin time

9:30 PM Goodnight!

Sunday, October 6th

7:15 AM Cold Breakfast

8:00 – 10:30 Children and Caregivers:
Infant play area, music, woodshop, arts and crafts, open gym

8:00 AM Parents: Introduction to Mindfulness

8:45 AM Parents: The Coming Era of Preventative Health in ALD: Finding the levers we can move (Keith Van Haren)

9:45 AM Parents: Closing Thoughts: Reflections on a larger view of health and wellness

10:45 AM Participant Check Out
Pack on cabin row

11:30 AM Lunch and Closing Ceremony

1:00 PM Participant Departure