UNITY
STRENGTH
HOPE

• JUNE 24-26, 2016 •
EAGLEWOOD RESORT - ITASCA, ILLINOIS
RETT SYNDROME, MECP2 DUPLICATION,
CDKL5 DISORDER & FOXG1 SYNDROME
DEAR FRIENDS,

On behalf of Rettsyndrome.org, the International Foundation for CDKL5 Research, the International FOXG1 Foundation and MECP2 Duplication’s 401Project | Cure MECP2, we welcome you to the 2016 Unity*Strength*Hope Family Education and Awareness Conference. We are glad you could join us in this significant year, as this year we come together as related disorders in the NIH RDCRN NCATS Natural History Study.

RETT SYNDROME celebrates the 50th anniversary since Dr. Andreas Rett first published his findings in an obscure Austrian Journal. Incredible advances have been made since that time, including participation by affected children in multiple clinical trials, the exponential growth in the number of Rett clinics to TWENTY-TWO in North America, resulting in significant progress in the quality of care for and understanding of our incredible children.

CDKL5 DISORDER celebrates having reached crucial milestones in translational science during our short time as a foundation. We have paved the way for strong clinical biomarkers to be established, which are necessary for the success of clinical trials on the horizon. Our core work includes collecting natural history, the development of multiple animal models and iPS cell lines and the creation of a CDKL5 clinical consortium. We are also proud to be advancing research through the NHS, biobanks and multiple related disorder partnerships.

FOXG1 SYNDROME celebrates the beginning of collaborations with researchers and clinicians to help individuals diagnosed with FOXG1.

MECP2 DUPLICATION celebrates the breaking news that MECP2 Duplications Syndrome is REVERSIBLE! In November of 2015, it was revealed that researchers at the Baylor College of Medicine, led by Dr. Huda Y. Zoghbi, have reversed MECP2 Duplication Syndrome in adult symptomatic mice using antisense oligonucleotide (ASO) gene therapy. This groundbreaking research shows that ASO gene therapy is a promising approach to treat MECP2 Duplication Syndrome. Further scientific studies must be conducted before this therapeutic approach can be tested on humans, but the BCM study is the first hurdle cleared of the many inherent to the drug development process.

Most of all, we celebrate our togetherness and our children. Conference is an incredible experience. We arrive separately, but we emerge together—smarter, empowered, recharged.

We wish to thank our organizing committee, sponsors, speakers, partners, supporters and volunteers because this conference would not be possible without you. Our special thanks to all attendees for making the journey to join in our shared mission to care for and reach for a cure for our children. Care and Cure are not mutually exclusive; they have been arm-linked since pre-modern times, rooted in the Latin curare: to care, to treat, to cure. Let us remain true to this goal in the present and future.

Hold tight—things are changing quickly for all of our disorders through medical and research advances. We are here to guide you through these fast-changing times. The future is here; let’s embrace and face it together.

Thank you for joining us,

Paige Nues
Rettsyndrome.org

Karen Utley
Amanda Jaksha
International Foundation for CDKL5 Research

Ileana Giordani
President of International FOXG1 Foundation

Dyna Mendoza
Levon’s Light & 401 Project | Cure MECP2 Duplication
### 2016 Family Conference Program Agenda

<table>
<thead>
<tr>
<th>Start Time</th>
<th>End Time</th>
<th>Session Topic</th>
<th>Speaker</th>
<th>Room</th>
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</thead>
<tbody>
<tr>
<td>Friday, June 24</td>
<td></td>
<td><strong>Abilities Expo Option</strong> (hotel shuttle depart 2pm, pickup 4pm, $5 each way, sign up at Rettsyndrome.org Registration Desk)</td>
<td>Renaissance Schaumburg Convention Center</td>
<td>Offsite</td>
</tr>
<tr>
<td>11:00</td>
<td>5:00</td>
<td><strong>Registration Desks and Research Readiness Arena open</strong> (fluid, open throughout conference)</td>
<td>Rettsyndrome.org: Red Oak IFCR, IFF, MECP2Dupl: Linden</td>
<td>1st Floor Conference Center Lobbies</td>
</tr>
<tr>
<td>12:30</td>
<td>6:30</td>
<td><strong>NIH NCATS RDCRN Rett syndrome, MECP2 Duplications, and Rett-Related Disorders (RTT) Consortium (2014–2019) (Researcher session that is also open to all parents, no children please)</strong></td>
<td>Alan Percy, MD, Professor, Pediatrics, Neurology, Neurobiology, Genetics, and Psychology, UAB, Jeffrey Neul, MD, PhD, Chief of Division of Neurology at Rady Children’s Hospital - UC San Diego, Walter Kaufmann, MD, Ravenel Boykin Curry Chair in Genetic Therapeutics, Greenwood Genetics Center, Timothy A. Benke, MD, PhD, Children’s Hospital Colorado, University of Colorado School of Medicine</td>
<td>Red Oak</td>
</tr>
<tr>
<td>1:30</td>
<td>3:00</td>
<td><strong>Focus Group for Communication Professionals</strong> <em>Special Event</em></td>
<td>Gillian Townend, B.Med.Sci. M.Phil.; Researcher and AAC Specialist, Rett Expertise Centre Netherlands - GKC, Maastricht University Medical Centre; Theresa Bartolotta, PhD, Dean,</td>
<td>Trillium Amphitheater</td>
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<tr>
<td>Time</td>
<td>Event</td>
<td>Speaker(s)</td>
<td>Location</td>
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<tr>
<td>2:00</td>
<td>Pulmonary Management</td>
<td>Girish Sharma, MD, FCCP, FAAP, Director Pediatric Pulmonology &amp; Rush CF Center</td>
<td>Lilac X X X X X</td>
<td></td>
</tr>
<tr>
<td>2:15</td>
<td>CDKL5: Getting involved with Research, Biobanking, and Science &amp; Database Updates</td>
<td>Alysson R. Muotri, PhD, Co-Director of the UCSD Stem Cell Program, University of California, San Diego, Helen Leonard, MBChB MPH, Telethon Kids Institute</td>
<td>Linden X</td>
<td></td>
</tr>
<tr>
<td>3:15</td>
<td>Genetics 101: What do MECP2, CDKL5, and FOXG1 have to do with one another?</td>
<td>Steven Skinner, MD, Senior Clinical Geneticist, Director, Greenwood Genetic Center, South Carolina</td>
<td>Lilac X X X X X</td>
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<tr>
<td>4:30</td>
<td>Rettsyndrome.org State Representative Meeting *Special event</td>
<td>Jennifer Endres, Andrea Reed</td>
<td>Indigo X</td>
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<tr>
<td>4:30</td>
<td>Centers of Excellence Clinical Coordinator Meeting *Special event</td>
<td>Jane Lane, Tristen Dinkel</td>
<td>Iris X X</td>
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<tr>
<td>4:30</td>
<td>Break</td>
<td></td>
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<tr>
<td>5:00</td>
<td>Dinner</td>
<td>Bring your meal ticket</td>
<td>Burnham’s Restaurant X X X X X</td>
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<tr>
<td>6:30</td>
<td>Welcome and Orientation</td>
<td>All Foundations</td>
<td>Red Oak X X X X X</td>
<td></td>
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<tr>
<td>7:00</td>
<td>Rettsyndrome.org: Research Strategy, Research Symposium Highlights, Clinical Trials</td>
<td>Steve Kaminsky, PhD, Rettsyndrome.org CSO with the Session Chairs from the Research Symposium</td>
<td>Red Oak X</td>
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<tr>
<td>7:05</td>
<td>CDKL5 Disorder: Progress Towards Standardization of Care</td>
<td>Timothy A. Benke, MD, PhD, Medical Director, Rett Clinic and Research Director, Neuroscience Institute, Children’s Hospital Colorado, University of Colorado School of Medicine, Tristen Dinkel, CNRN, CPN, RN, BSN, Rett Program Coordinator, Neuroscience Institute, Children’s Hospital Colorado</td>
<td>Linden X</td>
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<tr>
<td>7:05</td>
<td>IFF Family Meet and Greet Social</td>
<td>International FoxG1 Foundation</td>
<td>Bluestem (2nd floor) X</td>
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<tr>
<td>7:00</td>
<td>MECP2 Duplication Syndrome Family Meet</td>
<td>Levon’s Light &amp; The 401 Project I Cure MECP2</td>
<td>Hydrangea X</td>
<td></td>
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### Saturday, June 25th

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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<tbody>
<tr>
<td>7:00</td>
<td>Breakfast</td>
<td>Bring your meal ticket Burnham’s Restaurant</td>
</tr>
<tr>
<td>7:00</td>
<td>Rettsyndrome.org Family Empowerment Board Meeting</td>
<td><em>Special event</em> Jennifer Mosca Indigo</td>
</tr>
<tr>
<td>8:00</td>
<td>Rett Syndrome &quot;Must Knows&quot;</td>
<td>Alan Percy, MD, PI NIH Natural History Study, Interim Director, Civitan International Research Center Red Oak</td>
</tr>
<tr>
<td>9:00</td>
<td>Rettsyndrome.org Leadership Welcome</td>
<td>Gordon Rich, COO and Paige Nues, Director, Rettsyndrome.org Red Oak</td>
</tr>
<tr>
<td>8:00</td>
<td>CDKL5 101: What we know, where we’re headed, clinical trials</td>
<td>David G Frame, PharmD, University of Michigan, IFCR Scientific Advisory Board Linden</td>
</tr>
<tr>
<td>8:00</td>
<td>MECP2 Duplication 101</td>
<td>Bernhard Suter, MD, Assistant Neurology Professor, Blue Bird Circle Rett Center, Baylor College of Medicine, Sarika Peters, PhD, Hydrangea</td>
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<tr>
<td>Time</td>
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<td>Speaker</td>
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<tr>
<td>8:00</td>
<td>Recent Progress in FOXG1 Research</td>
<td>Alexander R. Paciorkowski, MD, Assistant Professor of Neurology, Pediatrics, and Biomedical Genetics, University of Rochester Medical Center</td>
</tr>
<tr>
<td>9:30</td>
<td>Neuro 101: Structure, Function and Neuroplasticity</td>
<td>Pam Diener, PhD, MS, OT/L, Developmental Neuroscientist, Pediatric Occupational Therapist, Georgetown University School of Medicine</td>
</tr>
<tr>
<td>10:00</td>
<td>Well Child and Adult Care Overview</td>
<td>Jane Lane, RN, BSN, University of Alabama at Birmingham Research Nurse Manager and Clinic Coordinator</td>
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<tr>
<td>10:15</td>
<td>Break</td>
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<tr>
<td>10:30</td>
<td>Autonomic, Psychological and Metabolic Abnormalities Basics</td>
<td>Jeffrey Neul, MD, PhD, Professor and Chief of Child Neurology University of California, San Diego Rady Children's Hospital</td>
</tr>
<tr>
<td>10:50</td>
<td>Epilepsy Basics</td>
<td>Alexander R. Paciorkowski, MD, Assistant Professor of Neurology, Pediatrics, and Biomedical Genetics, University of Rochester Medical Center</td>
</tr>
<tr>
<td>11:10</td>
<td>Gastroenterology: GI Motility</td>
<td>Kathleen J. Motil, MD, PhD, Professor of Pediatrics, Baylor College of Medicine USDA/ARS Children’s Nutrition Research Center, Texas Children’s Hospital</td>
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<tr>
<td>11:30</td>
<td>Sibling Panel</td>
<td>Facilitated by Mickie McCool</td>
</tr>
<tr>
<td>11:45</td>
<td>Does the Data from the Natural History Study Provide a Light in the Tunnel for Recently Diagnosed Families?</td>
<td>Daniel C. Tarquinio, DO, MS-Cl, Director, Rett Syndrome Clinic, Emory University, Children's Healthcare of Atlanta, Sarika Peters, PhD,</td>
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<tr>
<td>Time</td>
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<td>Speaker/Presenter</td>
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<tr>
<td>12:00</td>
<td>Lunch</td>
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<tr>
<td>12:00</td>
<td>Lunch</td>
<td>Burnham's Restaurant</td>
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<tr>
<td>12:30</td>
<td><em>Special Event</em></td>
<td>Jackie Piscatelli</td>
</tr>
<tr>
<td>1:15</td>
<td>Cortical Vision Impairment: What is CVI and How is it Treated?</td>
<td>Ellen Cadigan Mazel, M.Ed., Certified Teacher of Students with Visual Impairments, Deaf-Blindness and Cortical Visual Impairment, Concord Area Special Education Collaborative</td>
</tr>
<tr>
<td>1:30</td>
<td>Orthopedics: Scoliosis and Joint Contractures</td>
<td>Christopher Sullivan, MD, MPH, The University of Chicago Medicine</td>
</tr>
<tr>
<td>1:30</td>
<td>Behavior Issues and Management</td>
<td>Walter Kaufmann, MD, Director of the Center for Translational Research (CTR), Greenwood Genetic Center.</td>
</tr>
<tr>
<td>1:30</td>
<td>What Can Parents Expect from Services Supporting Their Child’s Communication? What do Professionals Need to Know to Offer Appropriate Communication Support?</td>
<td>Theresa Bartolotta, PhD, Dean, School of Health Sciences at Stockton University, Gillian Townend, B.Med.Sci. M.Phil.; Researcher and AAC Specialist, Rett Expertise Centre Netherlands - GKC, Maastricht University Medical Centre</td>
</tr>
<tr>
<td>1:30</td>
<td>Feeding and Swallowing Treatment and Management</td>
<td>Margaret Spring, MS, OT, Children’s Hospital Colorado Rett Clinic/CDKL5 Center of Excellence, expert nutritionist</td>
</tr>
<tr>
<td>2:30</td>
<td>Intensive Physical Therapy: An Option Worth Exploring</td>
<td>Bethany Hubbard, Doctorate of Physical Therapy, Achieve Health and Wellness, LLC</td>
</tr>
<tr>
<td>2:30</td>
<td>Movement Disorders</td>
<td>Bernhard Suter, MD, Assistant Neurology Professor, Blue Bird Circle Rett Center, Baylor College of Medicine</td>
</tr>
<tr>
<td>2:30</td>
<td>To Sleep, Perchance to</td>
<td>Judy Barrish, BSN, Nsg</td>
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</table>

*Special Event* indicates an event that is separate from the regular schedule.
<table>
<thead>
<tr>
<th>Time</th>
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<tbody>
<tr>
<td>2:30</td>
<td>Epilepsy Management: Treatments, Emergencies, SUDEP</td>
<td>Timothy A. Benke, MD, PhD, Medical Director, Rett Clinic and Research Director, Neuroscience Institute, Children’s Hospital Colorado, University of Colorado School of Medicine, Rebecca J. Schultz, PhD, RN, CPN, The Blue Bird Circle Rett Center with Baylor College of Medicine, Instructor - Clinical Nurse Practitioner, Director - First Seizure Clinic</td>
<td>Linden</td>
</tr>
<tr>
<td>3:00</td>
<td>Break</td>
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<tr>
<td>3:30</td>
<td>Nutrition Basics: Growth, Bone Health, Gut Function</td>
<td>Kathleen J. Motil, MD, PhD, Professor of Pediatrics, Baylor College of Medicine USDA/ARS Children’s Nutrition Research Center, Texas Children’s Hospital</td>
<td>Linden</td>
</tr>
<tr>
<td>3:30</td>
<td>Autonomic, Psychological, and Metabolic Abnormalities in RTT Disorders</td>
<td>Jeffrey Neul, MD, PhD, Professor and Chief of Child Neurology University of California, San Diego Rady Children’s Hospital</td>
<td>Lilac</td>
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<tr>
<td>3:30</td>
<td>Occupational Therapy and More</td>
<td>Jeanette Jones, MOT, OTRL, Occupational Therapist, Kaufman Children’s Center, West Bloomfield, MI</td>
<td>Arrowhead</td>
</tr>
<tr>
<td>3:30</td>
<td>Physiatry</td>
<td>Laura Deon, MD, Pediatric Rehabilitation Physician at Rush University Medical Center and Schwab Rehabilitation Hospital</td>
<td>Hollyhock</td>
</tr>
<tr>
<td>3:30</td>
<td>Boys and Puberty</td>
<td>Sarika Peters, PhD, Assistant Professor of Pediatrics, Vanderbilt University School of</td>
<td>Iris</td>
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### Medicine

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<th>Speaker/Presenter</th>
<th>Location</th>
<th>Notes</th>
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<tbody>
<tr>
<td>4:15</td>
<td>Womanhood 2016: From Puberty to Menopause</td>
<td>Jane Lane, RN, BSN, University of Alabama at Birmingham Research Nurse Manager and Clinic Coordinator</td>
<td>Lilac</td>
<td>X</td>
</tr>
<tr>
<td>4:15</td>
<td>Wearables and Monitors: how they fit into care and research</td>
<td>Daniel C. Tarquinio, DO, MS-CI, Director, Rett Syndrome Clinic, Emory University, Children’s Healthcare of Atlanta</td>
<td>Trillium Amphitheater</td>
<td>X</td>
</tr>
<tr>
<td>4:15</td>
<td>Medical Cannabis</td>
<td>Timothy Feyma, MD, Pediatric Neurologist, Gillette Children’s Specialty Healthcare</td>
<td>Linden</td>
<td>X</td>
</tr>
<tr>
<td>4:15</td>
<td>Dads Only Panel</td>
<td>Facilitated Panel</td>
<td>Hollyhock</td>
<td>X</td>
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<tr>
<td>5:00</td>
<td>Break</td>
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<tr>
<td>6:30</td>
<td>Large Group Children Photo</td>
<td>All Children, then by Disorder</td>
<td>TBD</td>
<td>X</td>
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<tr>
<td>7:00</td>
<td>Tribute Reception</td>
<td>Hosted by All Foundations</td>
<td>Red Oak Ballroom</td>
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### Sunday, June 26th

*Hotel Checkout 11am*

<table>
<thead>
<tr>
<th>Time</th>
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<th>Speaker/Presenter</th>
<th>Location</th>
<th>Notes</th>
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</thead>
<tbody>
<tr>
<td>7:00</td>
<td>Breakfast</td>
<td>Bring your meal ticket</td>
<td>Burnham Restaurant</td>
<td>X</td>
</tr>
<tr>
<td>8:15</td>
<td>General Welcome</td>
<td>All Foundations</td>
<td>Red Oak</td>
<td>X</td>
</tr>
<tr>
<td>8:20</td>
<td>Research Update: Communications Guideline Development</td>
<td>Theresa Bartolotta, PhD, Dean, School of Health Sciences at Stockton University, Gillian Townend, B.Med.Sci. M.Phil.; Researcher and AAC Specialist (with a background in SLP), Rett Expertise Centre Netherlands - GKC, Maastricht University Medical Centre</td>
<td>Red Oak</td>
<td>X</td>
</tr>
<tr>
<td>8:30</td>
<td>Literacy and Communication Any Time for Anyone</td>
<td>David Koppenhaver, PhD, Professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University, Karen Erickson, PhD, Director, Center for Literacy &amp; Disability Studies, University of North Carolina at Chapel Hill</td>
<td>Red Oak</td>
<td>X</td>
</tr>
<tr>
<td>Time</td>
<td>Session Title</td>
<td>Presenter(s)</td>
<td>Location</td>
<td>Notes</td>
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<tr>
<td>9:30</td>
<td>Communication: Getting Started or Starting Again</td>
<td>Karen Erickson, PhD, Director, Center for Literacy &amp; Disability Studies, University of North Carolina at Chapel Hill, Judy Lariviere, M.Ed., OTR/L, Assistive Technology Specialist &amp; Occupational Therapist, Katie’s Clinic for Rett Syndrome &amp; Related Disorders at UCSF Benioff Children’s Hospital Oakland &amp; Private Practice, Assistive Tech 4 ALL, Inc.</td>
<td>Red Oak</td>
<td>X</td>
</tr>
<tr>
<td>9:30</td>
<td>Communication Foundations for Writing: Play, Narrative Construction and Story Retell</td>
<td>Susan Norwell, MA Sped. Educational Specialist, Rett University</td>
<td>Linden</td>
<td>X</td>
</tr>
<tr>
<td>9:30</td>
<td>Emergent Literacy: Getting Started Any Time with Anyone</td>
<td>David Koppenhaver, PhD, Professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University</td>
<td>Trillium Amphitheater</td>
<td>X</td>
</tr>
<tr>
<td>9:30</td>
<td>IEP Beginning the Journey</td>
<td>Kate Ahern, MS Ed, Assistive Technology (AT) Specialist, Teacher of Learners with Multiple or Significant Special Needs, Easter Seals and Mickie McCool, Parent Advocate</td>
<td>Arrowhead</td>
<td>X</td>
</tr>
<tr>
<td>9:30</td>
<td>Moving Forward: Transition to Adult Care</td>
<td>Judy Barrish, BSN, Nsg Superv., Patient Manager/Project Coordinator at The Blue Bird Circle Rett Center with Baylor College of Medicine, with experienced parent facilitators</td>
<td>Lilac</td>
<td>X</td>
</tr>
<tr>
<td>9:30</td>
<td>Protected Tomorrows: Your Journey Through An Eight Step Special Needs Planning Program</td>
<td>Mary Anne Ehlert, CFP, President, Protected Tomorrows</td>
<td>Iris</td>
<td>X</td>
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<tr>
<td>10:30</td>
<td>Break</td>
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<tr>
<td>10:45</td>
<td>Formal and Informal Strategies for Problem</td>
<td>Matthew D. Cohen, JD Founder &amp; Principal</td>
<td>Iris</td>
<td>X</td>
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<tr>
<td>Time</td>
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<td>10:45</td>
<td>Solving When Special Education Isn't Working</td>
<td>Attorney, Matt Cohen &amp; Associates, Special Education, Disability Rights &amp; Human Services Law</td>
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<tr>
<td>11:45</td>
<td>Now What Do We Do? Life After High School</td>
<td>Sarika Peters, PhD, Assistant Professor of Pediatrics, Division of Developmental Medicine, Vanderbilt University, and Harriet Heydemann, Writer, Blogger, Parent, Advocate</td>
<td>Lilac</td>
<td></td>
</tr>
<tr>
<td>10:45</td>
<td>Successful Eye Gaze Trials: From Calibration to Communication</td>
<td>Judy Lariviere, M.Ed., OTR/L, Assistive Technology Specialist &amp; Occupational Therapist, Katie’s Clinic for Rett Syndrome &amp; Related Disorders at UCSF Benioff Children’s Hospital Oakland &amp; Private Practice, Assistive Tech 4 ALL, Inc.</td>
<td>Red Oak</td>
<td></td>
</tr>
<tr>
<td>11:45</td>
<td>Guided Reading: Learning to Read</td>
<td>Susan Norwell, MA Sped. Educational Specialist, Rett University and Kate Ahern, MS Ed, Assistive Technology (AT) Specialist, Teacher of Learners with Multiple or Significant Special Needs</td>
<td>Linden</td>
<td></td>
</tr>
<tr>
<td>10:45</td>
<td>Writing: Helping Everyone Get Started and Improve</td>
<td>David Koppenhaver, PhD, Professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University, Karen Erickson, PhD, David E. &amp; Dolores (Dee) Yoder Distinguished Professor of Literacy and Disability Studies, Director, Center for Literacy &amp; Disability Studies, University of North Carolina at Chapel Hill</td>
<td>Trillium Amphitheater</td>
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<tr>
<td>12:00</td>
<td>Closing Remarks</td>
<td>Rettsyndrome.org</td>
<td>Red Oak</td>
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<tr>
<td>12:00</td>
<td>The CDKL5 Community and Closing Remarks</td>
<td>International Foundation for CDKL5 Research</td>
<td>Linden</td>
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<tr>
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<tr>
<td>12:00</td>
<td><strong>International FOXG1 Foundation Closing Remarks</strong></td>
<td>International FOXG1 Foundation</td>
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<tr>
<td>12:00</td>
<td><strong>MECP2Duplication Families Closing Remarks</strong></td>
<td>Levon’s Light &amp; 401Project I Cure MECP2Duplication</td>
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<td>1:00</td>
<td>Lunch/Conference Ends</td>
<td>Bring your meal ticket</td>
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<tr>
<td>1:00</td>
<td><strong>Abilities Expo</strong></td>
<td>Offsite</td>
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<td>1:00</td>
<td>Additional Research Arena Activities</td>
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**Post Conference**

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speakers/Experts</th>
<th>Location</th>
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<tbody>
<tr>
<td>2:00</td>
<td>Post Conference Office Hours with Communication Experts</td>
<td>Judy Lariviere, Susan Norwell, Theresa Bartolotta, &amp; Gillian Townend</td>
<td>Arrowhead</td>
</tr>
<tr>
<td>2:00</td>
<td>Post Conference Office Hours with Literacy Experts</td>
<td>David Koppenhaver &amp; Karen Erickson</td>
<td>Hollyhock</td>
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<tr>
<td>2:00</td>
<td>Post Conference Office Hours IEP</td>
<td>Kate Ahern &amp; Mickie McCool</td>
<td>Fenthistle</td>
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<tr>
<td>3:30</td>
<td>Post Conference High-Tech Communication Hands-on Workshop</td>
<td>Judy Lariviere, Susan Norwell, and TobiiDynavox and PRC Reps</td>
<td>Arrowhead</td>
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</tbody>
</table>

*Post Conference sessions close no later than 5pm*

*Hotel checkout is 11am*

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“How wonderful it is that nobody need wait a single moment before starting to improve the world.”

–Anne Frank
REGISTRATION DESKS open at 12:30pm Friday. Pick-up your registration materials; badge; conference bag; photo button; Tribute Dinner and meal tickets. Don’t forget to drop off a Raffle item, and/or buy Raffle tickets for items at the Tribute Reception.

Rettsyndrome.org Registration Desk: outside the Red Oak Ballroom
CDKL5, FOXG1 and MECP2 Duplication Desks: outside the Linden Ballroom

FOUNDATION MERCHANDISE AND CONFERENCE T-SHIRTS will be on display and for sale at the registration desks. This is your chance to pick up something for yourself, or for that special educator, caregiver or loved one. Checks and credit cards are welcome.

HELP AND DIRECTIONS can be found at the Registration Desks. Don’t hesitate to ask; that is why we are here!

SESSIONS on a sensitive note, are only for adults and children over 12 who have paid a conference fee. Please wear your conference badge at all times. Please close doors quietly, showing consideration for speakers and attendees, and limit noise in hallways outside of session rooms. Please set cell phones to silent, vibrate, or airplane mode.

SESSION AUDIO RECORDINGS AND HANDOUTS Many session audio recordings and slides, when permitted by the speaker, will be posted to the website soon after the conference.

CONTINUING EDUCATION UNITS (CEU) CERTIFICATES are available for the professional. They are not accredited with national organizations, but we are happy to verify your hours and attendance. Please ask at the registration desk.

DRESS We encourage you to dress comfortably for the day sessions, and wear something a little nicer for the Saturday Tribute Reception. The weather in Chicago can be very warm and humid in June, while conference rooms can run cool, so plan accordingly and wear layers.

DINING OPTIONS AND LEISURE ACTIVITIES If you are a FULL REGISTRATION attendee please join us in the Burnham Restaurant for group meals. ONE DAY REGISTRATION includes meals and refreshments offered that day. In addition, one (1) Tribute Reception ticket is included for all FULL and ONE-DAY SATURDAY attendees.

Tickets are required at the door for all meals and can be found in your registration materials. Refreshment breaks are offered Saturday and Sunday for attendees. Please keep track of your Tribute Reception and meal tickets as they are non-replaceable. You may also pass them to a friend or turn them in at the Registration Desks if you won’t be attending, but they are non-refundable.

Travel companions have the option to self-pay and join us at Burnham’s Restaurant. Additional onsite dining options are the Prairie River Golf and Firepit Cafe, or The Market grab-and-go shop. These are not a part of the conference plan but are open to the public. Additional restaurants and shops are in the area; you can request a ride from the hotel shuttle. Check in your registration packet or with the Bellhop for this list.

The Saturday Tribute Reception is an evening event with cash bar, coffee and dessert only.

EVALUATION FORMS are important to help us improve our conference each year. Please complete the conference and session evaluation survey forms online. The link will be emailed to you before, during and after conference.

RESPITE If you pre-registered for Respite, please check-in at the Rettsyndrome.org Registration Desk upon arrival at the conference for Respite details. Thereafter, bring your children for Respite drop off and pickup promptly at your scheduled times at the Conference Center 2nd floor Bluestem Room. The Wheatgrass/Bottlebrush Rooms will also be utilized. With your cooperation and clear communication, all will have a good time with lots of activities and close support from our Respite providers and parent volunteers.

TRANSPORTATION The hotel has an on-demand, complimentary shuttle available to designated restaurants on a first come, first serve basis. Please see guest services for directions, reservations and transportation information. Travel to and from O’Hare and Midway airports is available from A-1 Limousine Service; private cars are available as well.
UNITY • STRENGTH • HOPE

Special Events, Programs and Activities

ABILITIES EXPO
Renaissance Schaumburg Convention Center Friday and Saturday 11am - 5pm and Sunday 11am - 4pm.
Free admission to the AE. Sign up at the registration desk for Friday hotel shuttle departure at 2pm, and AE pickup at 4pm. $5 each way, per person. Maximum 13 riders. Not WC accessible, but rear room for folding strollers or wheelchairs.

CENTERS OF EXCELLENCE CLINICAL COORDINATOR MEETING
A working meeting for the clinic coordinators. 4:30pm-5:30pm, Iris Room.

COMMUNICATION PROFESSIONALS FOCUS GROUP
Communication Professionals are invited to participate in this session to contribute to a Rettsyndrome.org funded international project to develop clinical guidelines for the assessment, intervention and long-term management of communication in Rett syndrome (RTT). Open to all community communication professionals, no fee or registration required. 2pm-4pm, Trillium Amphitheater.

CONTRIBUTE TO RESEARCH
Please visit our FAMILY RESEARCH READINESS ARENA for many ways you can help and participate in research opportunities through clinical trials, the NIH Natural History Study, biobanks, registries, databases, questionnaires, and onsite assessments if your child is with you. Cruise the Red Oak pre-function lobby area to view posters, visit tables of the experts, and check the Rettsyndrome.org registration desk for assessment signups in the Aster Room.

HAVE YOUR CHILD’S PHOTO TAKEN BY A PROFESSIONAL FOR AWARENESS MATERIALS
All disorders see Rettsyndrome.org registration desk in the Red Oak Pre-function lobby for Signup times. Children, families, professionals, researchers, volunteers and board members invited.

POST-CONFERENCE WORKSHOP
All disorder attendees check-in with the Rett syndrome.org registration desk to confirm your pre-registration and for additional information, or if you missed pre-registering, you may still register onsite at the registration desk if space is available.

RETTSYNDROME.ORG STATE REPRESENTATIVE MEETING
Meet Jennifer Endres, Andrea Reed and Jen Mosca on Friday from 4:30pm-5:30pm for annual bonding and planning! Indigo Room

RETTSYNDROME.ORG STROLLATHON CHAIR MEETING
Meet Jackie Piscatelli on Saturday 12:30pm-1:30pm for planning and Q/A! Grab your lunch to-go from the Burnham Restaurant then head over to the Indigo Room.

TRIBUTE RECEPTION, AWARDS, ENTERTAINMENT AND GROUP PICTURES
Dress a little nicer for an evening of fun and celebration. Please arrive early with your beautiful children for group picture at 6:30pm. Red Oak Ballroom opens at 7pm. Bring your Tribute Ticket to attend!

TRIBUTE RECEPTION RAFFLE
You are sure to find something you can’t live without in the collection of items up for Raffle! Purchase your Raffle tickets at the Registration Desk, Bookstore, at the event, or from one of our wandering ticket selling volunteers. At the Tribute Reception, drop your ticket(s) into the container for a chance at the wonderful item(s) of your choice, including a Convaid Trekker! The more tickets you drop in, the better your chances are of winning that item. Raffle winners will be drawn and announced Saturday night at the Tribute Reception. All proceeds benefit conference.
THANK YOU TO EACH OF OUR SPONSORS, PARTNERS, SUPPORTERS AND FRIENDS. YOUR HELP IS OUR HOPE!

“No one is more cherished in this world than someone who lightens the burden of another.”

Hosts

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Achieve Health and Wellness, LLC
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Baylor College of Medicine/Texas Children’s Hospital
Children’s Hospital Boston/Harvard Medical School
Children’s Hospital Colorado/University of Colorado School of Medicine
Concord Area Special Education Collaborative
Easter Seals
Emory University Hospital
Georgetown University School of Medicine
Gillette Children’s Specialty Healthcare
Greenwood Genetic Center
Kaufman Children’s Center
Maastricht University Medical Centre, Netherlands
Matt Cohen & Associates, Special Education, Disability Rights & Human Services Law
Protected Tomorrow’s
Rett University
Rush University Medical Center
School of Health Sciences at Stockton University
Telethon Kids Institute, Australia
University of Alabama, Birmingham
University of California San Diego/Rady Children’s
University of California San Francisco Benioff Oakland Children’s Hospital
University of Chicago
University of North Carolina at Chapel Hill
University of Rochester Medical Center
Vanderbilt University School of Medicine
Autonomic Dysfunction. People with Rett syndrome and related disorders have a variety of autonomic and physiological issues. The most appreciated is the abnormal breathing patterns that include hyperventilation and breath holding, but other significant abnormalities are also present. These include cardiac rhythm abnormalities, cold or hot hands or feet, abnormal sweating and gastrointestinal function. Many of these autonomic abnormalities are present in the animal models, and these models can provide insight into the mechanism and possible treatment options for these problems. The animal models have also demonstrated that additional physiological and metabolic abnormalities can occur in Rett syndrome. In this talk, Dr. Neul will review the known clinical abnormalities in autonomic, physiologic, and metabolic systems in Rett syndrome and discuss possible treatment approaches. Additionally, Dr. Neul will present knowledge from translational research on these subjects. Jeffrey Neul, M.D., Ph.D., Chief of Division of Neurology at Rady Children’s Hospital - UC San Diego. Saturday, 3:30-4:15

Autonomic, Psychological and Metabolic Abnormalities Basics: People with Rett syndrome and related disorders have a variety of autonomic, physiological, and metabolic issues. This session will be an abbreviated symptom overview for general session attendees. Jeffrey Neul, M.D., Ph.D., Chief of Division of Neurology at Rady Children’s Hospital - UC San Diego. Saturday, 10:30-10:45

Behavior Issues and Management. It has been recently recognized that girls and women with Rett syndrome (RTT) display a wide range of behavioral problems and that these can substantially affect quality of life. Thus, diagnosis and management of behavioral problems should be a major component of clinical evaluations in RTT. The first step is a detailed characterization of the behavior using available questionnaires. Then, physical causes of discomfort that could lead to abnormal behavior should be ruled out. After concluding that the abnormal behavior is not due to other medical issues or to impairments in communication, the appropriate treatment should be selected. In addition to drugs that are prescribed for other neurodevelopmental disorders, behavioral therapies could be helpful. A careful evaluation of home and school environments could also identify situations that can trigger problematic behaviors and can be easily corrected. These issues and research efforts at improving diagnosis and treatment in RTT will be covered in detail during the presentation. Walter Kaufmann, M.D., Director of the Center for Translational Research (CTR), Greenwood Genetic Center. Saturday, 1:30-2:20

CDKL5: Getting involved with Research, Biobanking, and Science & Database Updates Dr. Muotri will update on research progress using CDKL5 iPSCs for disease modeling and drug screening. Dr. Leonard will begin by describing the development of our international CDKL5 database and its current status. I, Dr. Leonard, will elaborate on the wonderful contributions we have had from families around the world and what this has meant for advancement of knowledge about this disorder. I will also explain how new families can participate in this important research. I will present data on what we know about developmental milestones in CDKL5 and the range of functioning among those affected. I will present our most up to date results on epilepsy and other medical conditions that may occur in this disorder and explain how these compare with Rett syndrome. Finally, I will report new results looking at how having a child with the CDKL5 disorder may affect the family and outline what factors we have shown to be protective for family wellbeing as well as those which may have adverse effects. Alysson R. Muotri, Ph.D. Associate Professor, Co-Director of the UCSD Stem Cell Program, University of California, San Diego, Helen Leonard, MBChB MPH, Telethon Kids Institute. Friday, 2:15-3:15
CDKL5 101: What we know, where we’re headed, clinical trials. A discussion of the basic science of CDKL5, what we know and where we are headed, as well as an update on the latest scientific research and highlights from IFCR’s 3rd International Research Symposium held earlier in the week. Learn about the latest results that give more insight into the CDKL5 disorder phenotype and spectrum. Also learn how you can participate, and why participation is so important to all scientific and clinical research. David G Frame, Pharm.D, University of Michigan, IFCR Scientific Advisory Board. **Saturday, 8:00-9:15**

CDKL5 Disorders: Progress Towards Standardization of Care: Standards of care have not yet been established for CDKL5 syndrome. Key questions involve the management of epilepsy, GI, pulmonary, musculoskeletal and cardiac issues, and the provision of appropriate therapies and equipment to name a few. In addition, parents and families need support. Towards this goal, we have established a model of care in our IFCR Center of Excellence in the Rett Clinic at Children’s Hospital Colorado. This clinic is generously sponsored by Rocky Mountain Rett Association (RMRA). Through research supported by IFCR and the NIH Natural History study, we hope to determine the most effective approaches to care. In this session we will review what a day at clinic looks like for the patient family. Timothy A. Benke, MD, PhD, Ponzio Family Endowed Chair in Neurology Research, Medical Director, Rett Clinic and Research Director, Neuroscience Institute, Children’s Hospital Colorado, Associate Professor Depts. of Pediatrics, Neurology, Pharmacology & Otolaryngology, University of Colorado School of Medicine, Tristen Dinkel, CNRN, CPN, RN, BSN, Rett Program Coordinator, Neuroscience Institute, Children’s Hospital Colorado. **Friday, 7:10-8:00**

The CDKL5 Community and Closing Remarks: Learn the many ways you can support the IFCR’s mission, including how to participate in CDKL5 translational research. We will discuss raising awareness, fundraising for the foundation, and volunteering opportunities. International Foundation for CDKL5 Research Board of Directors. **Sunday, 12:00-1:00**

Communication Foundations for Writing: Play, Narrative Construction and Story Retell. If you can write, you can communicate anything you want. Writing is therefore an essential form of communication and is in fact, quickly becoming “my girls” favorite activity. While the experience of actually writing combined with finding the kiddos’ pencil is essential to developing the skill of writing, understanding foundational communication skills for writing will help parents, therapists and teachers develop the ideation skills that support the content of writing. In this session we will explore Play, as the “work” of early childhood, and its support in creating a simple story with a beginning middle and end. The Communication skills of Narrative Construction and Story Retell help young communicators practice and play with creating stories of their own that can later become their language written down. Rich videos will highlight the “how to’s” of developing these important foundational skills that expand the ideation supporting the content of writing. (See David Koppenhaver and Karen Erickson’s Session). Susan Norwell, M.A. Sped. Educational Specialist, Rett University. **Sunday, 9:30-10:30**
Communication: Getting Started or Starting Again. This session will focus on supporting communication development for individuals with Rett syndrome and related disorders (young and old), who do not already have a formal means of communication. Whether you have a young child who is newly diagnosed or an adolescent or adult who has struggled to find a way to communicate, this session is for you. We will focus on recognizing and acknowledging existing communication attempts. Then we will describe strategies to build on them. Specific attention will be given to the use of communication supports in naturally occurring interactions that focus on using symbols to communicate and interact (instead of identifying the symbols). We will use videos and provide specific examples of low-tech communication systems that will let you get started or get started again in helping your son/daughter/student communicate more effectively. We will also be sharing some materials that can help you get started with communication right away! Karen Erickson, PhD, Director, Center for Literacy & Disability Studies, University of North Carolina at Chapel Hill, Judy Lariviere, M.Ed., OTR/L, Katie’s Clinic for Rett Syndrome, UCSF Benioff Children’s Hospital Oakland and Private Practice, Assistive Tech 4 ALL. Sunday, 9:30-10:30

Communication Research Update: Communications Guideline Development: In February 2016 rettsyndrome.org funded a two-year project to develop international clinical guidelines for the assessment, intervention and long-term management of communication in individuals with Rett syndrome. Currently there is huge variability in knowledge, expertise, and clinical practice between and within countries. Guidelines are needed to provide direction for families and clinicians. Led by the Rett Expertise Centre Netherlands, an international consortium (see authors) has begun work to combine ‘available evidence’ with ‘expert consensus’, following the model of previous guidelines relating to RTT. The project will draw on published and unpublished literature as well as the experiences of individuals with RTT, their families and professionals from as many countries as possible. In this session a brief overview of progress to date will be presented together with information on how interested parents and professionals can make a contribution to the project. Theresa Bartolotta, PhD, Dean, School of Health Sciences at Stockton University, Gillian Townend, B.Med.Sci. M.Phil.; Researcher and AAC Specialist (with a background in SLP), Rett Expertise Centre Netherlands - GKC, Maastricht University Medical Centre. Sunday, 8:20-8:30

Cortical Vision Impairment: What is CVI and How is it Treated? Cortical Visual Impairment (CVI) is known to affect children with RTT related disorders. This lecture will cover the basics of CVI and discuss assessment and strategies for children’s optimal visual learning. Ellen Cadigan Mazel, M.Ed., Certified Teacher of Students with Visual Impairments, Deaf-Blindness and Cortical Visual Impairment, Concord Area Special Education Collaborative. Saturday, 8:20-8:30

Dads Only Panel: Dads are special people to begin with; however, a dad to a child with Rett syndrome, CDKL5, FoxG1, or MECP2 Duplication disorder is even more special. This “dads only” session will provide an opportunity for you to interact with other dads in a very honest and genuine way allowing you to learn more about your child and yourself. Come join the camaraderie and leave with a few new friends. Facilitated Panel. Saturday, 4:15-5:00
**UNITY • STRENGTH • HOPE**

Does the data from the natural history study provide a light in the tunnel for recently diagnosed families? Daniel Tarquinio, D.O., M.S., Epileptologist, Assistant Professor, Emory University, Sarika Peters, Ph.D., Assistant Professor of Pediatrics, Division of Developmental Medicine, Vanderbilt University School of Medicine.

*Saturday, 11:45-12:15*

**Emergent Literacy:** Getting Started Any Time with Anyone. In this presentation we will dig deeper principles and practices for getting started with literacy with any and all individuals with significant disabilities regardless of age or disabilities. We will clarify the differences in goals and practices between emergent and conventional literacy and how to know when to implement both. We will share easily implemented teaching and assessment strategies. David Koppenhaver, PhD, Professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University.

*Sunday, 9:30-10:30*

**Epilepsy Basics:** This presentation will cover some of the common challenges facing individuals with epilepsy, including treatment. Alexander R. Paciorkowski, M.D., Assistant Professor of Neurology, Pediatrics, and Biomedical Genetics, University of Rochester Medical Center.

*Saturday, 10:50-11:05*

**Epilepsy Management:** Treatments, Emergencies, SUDEP. This session will focus on the management of seizures with antiepileptic medications, vagus nerve stimulation, and high-fat dietary therapy. Emergency management of seizures, seizure first aid, and the risk for SUDEP will also be discussed. Unfortunately, no particular anticonvulsant therapy works for all. However, literature and our experiences treating patients with MeCP2, CDKL5 and FOXG1 will be provided. Research and drug development needs will be highlighted. Timothy A. Benke, MD, PhD, Ponzio Family Endowed Chair in Neurology Research, Medical Director, Rett Clinic and Research Director, Neuroscience Institute. Children’s Hospital Colorado, Associate Professor Depts. of Pediatrics, Neurology, Pharmacology & Otolaryngology, University of Colorado School of Medicine, Rebecca J. Schultz, Ph.D., RN, CPN, The Blue Bird Circle Rett Center with Baylor College of Medicine, Instructor - Clinical Nurse Practitioner, Director - First Seizure Clinic.

*Saturday, 2:30-3:30*

**Feeding and Swallowing Treatment and Management:** This session will review normal development of feeding and compare it with common problems seen in the CDKL5 and related disorders population. We will review feeding strategies with this population including food textures, strategies to improve caloric intake, how to support oral feeding when a gastrostomy tube is in place, and instrumental evaluations of swallowing to assess current level of swallowing function. A case study will be presented which follows a young girl through a feeding and swallowing evaluation early on in her development to current day. Margaret Spring, MS, OT, Children’s Hospital Colorado Rett Clinic/CDKL5 Center of Excellence, expert nutritionist.

*Saturday, 1:30-2:20*

**MACKENZIE - RTT**

**Formal and Informal Strategies for Problem Solving When Special Education Isn’t Working.** Matt Cohen will discuss strategies to use when it seems like IDEA or the IEP process is breaking down. What can be done, what your rights are as parents and strategies to try will all be addressed. Matt will also discuss the more formal process of resolution, mediation and due process and what those processes involve. Matthew D. Cohen, J.D. Founder & Principal Attorney, Matt Cohen & Associates, Special Education, Disability rights & Human Services Law.

*Sunday, 10:45-11:45*
Gastroenterology: GI Motility. Gastrointestinal problems commonly found in Rett syndrome and related disorders include chewing and swallowing difficulties, feeding refusal, gastroesophageal reflux, delayed gastric emptying, gas bloating and constipation. These problems are caused by dysmotility of the gastrointestinal tract, presumably because of abnormalities in the enteric nervous system. Any symptom that causes parental concern should be evaluated by a physician. Parents should understand the basic diagnostic tests and treatment strategies that will improve symptoms, avoid complications, and improve their child’s quality of life.

Kathleen J. Motil, MD, PhD, Professor of Pediatrics, Baylor College of Medicine. USDA/ARS Children’s Nutrition Research Center, Texas Children’s Hospital. Saturday, 11:10-11:25

Genetics 101: What do MECP2, CDKL5, and FOXG1 have to do with one another? We will explore the clinical similarities and differences seen in patients with genetic changes in MECP2, CDKL5 and FOXG1. We will explore a basic understanding of these three genes (MECP2, CDKL5 and FOXG1) and how they are related to one another and to our understanding of Rett syndrome and Rett-related disorders. Steven Skinner, MD, Senior Clinical Geneticist, Director, Greenwood Genetic Center, South Carolina. Friday, 3:15-4:30

Guided Reading: Learning to Read. This workshop is designed to teach parents and professionals how to begin teaching the actual act of reading individuals with Rett syndrome. Often our students are relegated to just listening to books or even less, relentlessly identifying pictures in readiness for reading. This workshop focuses on Guided Reading within the Balanced Literacy Model as conceptualized by Patricia and Jim Cunningham. Videos will demonstrate strategies for beginning reading instruction. Parents and professionals will come away with a knowledge of the possibilities for complex kiddos and some specific strategies for beginning solid literacy instruction. Susan Norwell, M.A. Sped. Educational Specialist, Rett University and Kate

IEP Beginning the Journey. Mickie McCool is a trained Parent Advocate and has helped scores of families in the IEP process. Kate Ahern taught learners with significant special needs including complex communication needs for fifteen years and currently works as a consult in school districts and for families - specializing in Rett syndrome and other apraxia related communication disorders. In this session, Mickie will underscore the importance, the value, and practical how-to’s in building partnerships with administrators and educators for the ultimate benefit of the child, regardless of the setting. Kate will share sample IEP goals, including how to write goals for those who are "consistently inconsistent" because of apraxia or medical issues. She will also share insider tips on how to avoid pitfalls in IEP process that may impact student success as well as how to help teams see your child and all the strengths and gifts she or he has during what can be a very negative process. Both Mickie and Kate will share practical steps from real-life experiences, and will be available to talk more in-depth at the Sunday Post-Conference Office Hours. Kate Ahern, M.S.Ed, Assistive Technology (AT) Specialist, Teacher of Learners with Multiple or Significant Special Needs, Easter Seals and Mickie McCool, Parent Advocate. Sunday, 9:30-10:30
Intensive Physical Therapy: An Option Worth Exploring. The Intensive Therapy model offers many benefits to the therapist and the patient. It gives the therapist adequate time to prepare the patient for therapy and to focus on strengthening of specific muscle groups. There is improved day-to-day carryover associated with consecutive days in therapy, allowing the patient to build on each day’s gains to reach the “next level” functionally. Intensive Therapy can also be very helpful for patients who have reached a plateau with traditional therapy by providing the extra time and focus needed to progress. Immediately before or after surgical or other intervention, such as selective percutaneous myofascial lengthening (Percs) or alcohol blocks, an Intensive Therapy session can help build up the body to improve outcomes and take advantage of new range of motion. Bethany Hubbard, PT, DPT, Achieve Health & Wellness, LLC.

Saturday, 2:30-3:20

International FoxG1 Foundation Closing Remarks. Reflection on this past year’s accomplishments and the Foundations future goals.

Light in the Tunnel: Family Quality of Life Study Does the data from the Natural History Study provide a light in the tunnel for recently diagnosed families? This session will be a review of Quality of Life data collected from 10 years worth of thousands of observational visits from the Natural History Study, and will include problem-solving and coping strategies. Saturday, 11:45am - 12:15pm

Literacy and Communication Any Time for Anyone: In this presentation we will address important principles and practices for initiating and supporting literacy and communication in children, adolescents, or adults with Rett syndrome and other significant disabilities. Particular attention will be directed toward methods that can be implemented across home and school environments regardless of access to technologies. David Koppenhaver, PhD, Professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University, Karen Erickson, PhD, David E. & Dolores (Dee) Yoder Distinguished Professor of Literacy and Disability Studies, Director, Center for Literacy & Disability Studies, University of North Carolina at Chapel Hill. Sunday, 8:30-9:20

MECP2 Duplication 101: In this session, we will cover the basics of genetics, diagnosis, treatment, and management of MECP2 Duplication syndrome. We will also briefly discuss the latest research initiatives. The audience will share in the discussion with comments and questions. Bernhard Suter, M.D., Assistant Neurology Professor, Blue Bird Circle Rett Center, Baylor College of Medicine, Sarika Peters, Ph.D., Assistant Professor of Pediatrics, Division of Developmental Medicine, Vanderbilt University. Saturday, 8:00-9:15

Medical Cannabis: In this session we will discuss the details of Cannabis in regard to usage for Neurologic purposes. Timothy Feyma, M.D., Pediatric Neurologist, Gillette Children's Specialty Healthcare. Saturday, 4:15-5:00

Moving Forward: Transition to Adult Care Discussion of issues to be addressed as our kiddos move into the world of adult care medicine. Judy Barrish, BSN, Nsg Superv., Patient Manager/Project Coordinator at The Blue Bird Circle Rett Center with Baylor College of Medicine, with experienced parent facilitators. Sunday, 9:30-10:30

Movement Disorders: This session will focus on the most common movement disorders that occur in Rett syndrome and current approaches to treatment. Where indicated, comparisons to the other Rett-related disorders will be made. Bernhard Suter, M.D., Assistant Neurology Professor, Blue Bird Circle Rett Center, Baylor College of Medicine. Saturday, 2:30-3:20
NIH NCATS RDCRN Rett Syndrome, MECP2 Duplication, and Rett-Related Disorders (RTT) Consortium (2014–2019): Families and researchers alike are invited to this closing session of the 2016 Research Symposium as PI Panelists discuss the Rett syndrome, MECP2 Duplication, and Rett-Related Disorders (RTT) Consortium (2014–2019), led by Alan Percy, M.D. The goals of this consortium are far-reaching with the expansion to 14 sites, each one studying all related disorders, with NIH and the PIs working in tight collaboration with our Patient Advocacy Groups. This study is funded by the NIH Offices of NCATS, NICHD, NINDS, Rettsyndrome.org and is co-administered by Rettsyndrome.org. This session will include: Overview, Biospecimen Project, Building Behavioral Assessment Tools, Neurophysiologic Responses, and CDKL5 Specific Activities (Researcher session that is also open to all parents, no children please). Alan Percy, M.D., Professor, Pediatrics, Neurology, Neurobiology, Genetics, and Psychology, UAB, Jeffrey Neul, M.D., Ph.D, Chief of Division of Neurology at Rady Children’s Hospital - UC San Diego, Walter Kaufmann, M.D., Ravenel Boykin Curry Chair in Genetic Therapeutics, Greenwood Genetics Center, Timothy A. Benke, MD, PhD, Ponzio Family Endowed Chair in Neurology Research, Medical Director, Rett Clinic and Research Director, Neuroscience Institute, Children’s Hospital Colorado, Associate Professor Depts. of Pediatrics, Neurology, Pharmacology & Otolaryngology University of Colorado School of Medicine. 

Friday 1:30-3:00

Neuro 101: Structure, Function and Neuroplasticity: How do different areas of the brain function? How are they affected or influenced by our environment, training, and/or practice? This session will discuss these concepts and introduce some research in Rett syndrome (RTT) and related fields which show promise for improving motor control in individuals with RTT. Pam Diener, PhD, MS, OT/L, Developmental Neuroscientist, Pediatric Occupational Therapist, Georgetown University School of Medicine.

Saturday, 9:30-10:00

Now What Do We Do? Life After High School: Preparing for day programs & living arrangement options for the adult, beginning to look ahead in the high school IEP and re-envisioning if you’re already there. Harriet will share a unique program that was developed by and for a young woman with Rett syndrome. We will explain why an individualized program, versus a group day program, was the only program that was appropriate for her. I will discuss how I determined the specific components of the program, how I worked with her small team of specialists to satisfy her requirements and specifications, and where I secured the financial resources. Her successful program included:

- intellectual stimulation
- creative expression
- exploration of new ideas and places
- community involvement
- growth and learning opportunities
- flexibility
- and above all -- fun

Sarika Peters, Ph.D., Assistant Professor of Pediatrics, Division of Developmental Medicine, Vanderbilt University, and Harriet Heydemann, Writer, Blogger, Parent, Advocate.

Sunday, 10:45-11:45

Nutrition Basics: Growth, Bone Health, Gut Function: Malnutrition is common in Rett syndrome and related disorders and is causally associated with inadequate dietary intakes due to chewing and swallowing difficulties, as well as gastrointestinal dysfunction. The body mass index (BMI), a measure of the proportion of body weight in relation to body height and size, is the primary determinant of nutritional status in Rett syndrome. Parents should understand the basic nutritional needs for normal growth and bone health and recognize the gastrointestinal factors that may interfere with feeding. Good nutrition has beneficial growth and bone health outcomes and improves quality of life in individuals with Rett syndrome and related disorders. Kathleen J. Motil, MD, PhD, Professor of Pediatrics, Baylor College of Medicine USDA/ARS Children’s Nutrition Research Center, Texas Children’s Hospital.

Saturday, 3:30-4:15
**Occupational Therapy and more:** This session discusses the wide variety of areas that are addressed during individual occupational therapy sessions for RTT related disorders. A specific case study for a child with CDKL5 is explored in depth to assist practitioners in broadening their treatment ideas and areas of practice to promote improved functioning and independence for children of this population. Treatment approaches and areas include sensory integrative techniques, activities of daily living, brief touch on oral motor strengthening, as well as fine motor development and skill acquisition. Importance of integrating all disciplines is also discussed in order to better serve children and their families. Jeanette Jones, MOT, OTRL, Occupational Therapist, Kaufman Children’s Center, West Bloomfield, MI. **Saturday, 3:30-4:15**

**Physiatry:** How rehabilitation can offer improved care and comfort for children with Rett syndrome including management of spasticity and proper equipment for care at home and at school. Laura Deon, M.D, Pediatric Rehabilitation Physician at Rush University Medical Center and Schwab Rehabilitation Hospital. **Saturday, 3:30-4:15**

**Protected Tomorrows:** Your Journey Through an Eight Step Special Needs Planning Program: This presentation will be uplifting and educational. Participants will develop the foundation for their family’s own personal Eight Step Future Care Plan™. Topics of discussion include: how to create a map of the future; how to prepare legally and financially; how to incorporate and maximize government benefits; how to prepare for transition; and how to communicate your Future Care Plan™ to your family. Mary Anne Ehlert, CFP, President, Protected Tomorrows. **Sunday, 9:30-10:30**

**Boys and Puberty:** Come and learn about an area that is often ignored and can be difficult to discuss! In this session, we will discuss medical and behavioral approaches to the management of puberty in boys. There will be opportunities for questions, comments, and shared experiences. Sarika Peters, Ph.D., Assistant Professor of Pediatrics, Division of Developmental Medicine, Vanderbilt University School of Medicine. **Saturday, 3:30-4:15**

**Pulmonary Management of a Child with Rett Syndrome:** Patients with neuromuscular disorders such as Rett syndrome tend to have pulmonary involvement due to multiple causes including abnormal tone, muscle weakness, swallowing and feeding difficulties resulting in aspiration and recurrent pneumonia, abnormal breathing pattern and side effects of some medications. Causes and mechanism of such problems, management of respiratory infection and prevention of complications such as recurrent respiratory infections and maintenance of lung health will be discussed. Discussion will also include various airway techniques and devices used to maintain lung health and prevent respiratory infections. Girish Sharma, MD, FCCP, FAAP, Director of Pediatric Pulmonology & Rush CF Center. **Friday, 2:00-3:00**

**Recent progress in FOXG1 research.** This presentation will provide an update on the recent progress in FOXG1 research, with an emphasis on aspects of developmental disorders, epilepsy disorders and movement disorders. There will be 30 min. allotted to parent questions. Alexander R. Paciorkowski, M.D., Assistant Professor of Neurology, Pediatrics, and Biomedical Genetics, University of Rochester Medical Center. **Saturday, 8:00-9:15**

**Rettsyndrome.org:** Research Strategy, Research Symposium Highlights, Clinical Trials. Steve Kaminsky, PhD, Rettsyndrome.org CSO with the Session Chairs from the Research Symposium. **Friday, 7:10-8:00**

**Rettsyndrome.org Closing Remarks** Learn about the many new support projects and programs just for you, our families. Discover programs and ways you can support Rettsyndrome.org’s mission, including how to participate in research, raise awareness, fundraiser and volunteer for the foundation. **Sunday, 12:00-1:00**
**Scoliosis and Joint Contractures in Rett Syndrome.** Musculoskeletal aspects of Rett syndrome include scoliosis and joint contractures. 2/3 of girls get scoliosis and 60% need treatment for scoliosis, either bracing or spinal fusion. Risks and benefits of each will be described. Procedures of Posterior Spinal Fusion with Segmental Spinal Instrumentation will be explained and demonstrated, as will expected results. Patient and family experience after surgery will be described. Surgery for treatment of lower extremity contractures will also be discussed. Christopher Sullivan, MD, MPH, The University of Chicago Medicine. **Saturday, 1:30-2:20**

**Siblings Panel.** Don’t miss one of the highlights of conference! The Siblings Panel, open to everyone, is a touching and meaningful session where siblings of individuals with RTT Disorders share their experiences and life’s lessons. Siblings, ranging in age, proudly share what it is like to have such a special sibling in an honest and heartfelt way. Facilitated panel. **Saturday, 11:30-11:45**

"The best way to find yourself, is to lose yourself in the service of others."

— Ghandi

**Successful Eye Gaze Trials:** From Calibration to Communication: Individuals with Rett syndrome (RTT) and related disorders communicate volumes through their eyes; eye gaze technology taps directly into where they naturally look. All too often, families are faced with barriers to having an eye gaze system funded for their son or daughter. In this session, the setup and process that has enabled over 300+ individuals with RTT and related disorders across all ages to communicate using an eye gaze system, beginning with their first trial, will be discussed and highlighted through video examples. Strategies for calibrating, positioning, and configuring an eye gaze system to accommodate for an individual’s vision needs, including strabismus and cortical vision impairment, will be demonstrated. In addition, methods for documenting communication intent with purposeful selections without “testing” and/or tapping into apraxia will be highlighted. The influence of sensory regulation on communication when using an eye gaze system will also be shared. Judy Lariviere, M.Ed., OTR/L, Assistive Technology Specialist & Occupational Therapist, Katie’s Clinic for Rett Syndrome & Related Disorders at UCSF Benioff Children’s Hospital Oakland & Private Practice, Assistive Tech 4 ALL, Inc. Sunday, 10:45-11:45

To Sleep, Perchance to Dream: Sleep disruption issues and suggested methodologies will be discussed in this session. Judy Barrish, BSN, NSG Superv., Patient Manager/Project Coordinator at The Blue Bird Circle Rett Center with Baylor College of Medicine. **Saturday, 2:30-3:20**

**Wearables and Monitors: How They Fit Into Care and Research.** Daniel Tarquinio, D.O., M.S., Epileptologist, Assistant Professor, Emory University. **Saturday, 4:15-5:00**

**Well Child and Adult Care Overview.** During this session, general health maintenance recommendations will be discussed, including immunizations and periodic well visits for the diagnosed child and adult. Jane Lane, RN, BSN, University of Alabama at Birmingham Research Nurse Manager and Clinic Coordinator. **Saturday, 10:00-10:15**
What Can Parents Expect From Services Supporting Their Child’s Communication?
What Do Professionals Need to Know to Offer Appropriate Communication Support? There is huge variability in knowledge, expertise, and clinical practice between and within countries. Guidelines on assessment, intervention and support for communication are needed to provide direction for families and clinicians. In February 2016 an international project was funded by rettsyndrome.org to develop such guidelines. This two-year project is led by the Rett Expertise Centre Netherlands and combines ‘available evidence’ with ‘expert consensus.’ Reviews of published and unpublished literature and an inventory of clinical practices will underpin guidelines which will be confirmed by expert and parent groups using a ‘Delphi’ process. In this interactive session the presenters will provide an overview of the project to date and participants will be asked to share issues confronting them in relation to communication support. Their critical feedback will help inform the project. Theresa Bartolotta, PhD, Dean, School of Health Sciences at Stockton University, Gillian Townend, B.Med.Sci. M.Phil.; Researcher and AAC Specialist (with a background in SLP), Rett Expertise Centre Netherlands - GKC, Maastricht University Medical Centre. Saturday, 1:30-2:20

Womanhood 2016: From Puberty to Menopause: Women in this decade are thought to be maturing earlier and yet have many options with regard to choices and care. The same is true for women with Rett syndrome, CDKL5 disorder, FOXG1 syndrome, or MECP2 Duplication. This session gives up-to-date information about the maturation process from onset of puberty to menopause, findings of the Rett Syndrome Natural History Study as it relates to puberty and menarche, the role that hormones play with seizures, options for management of menstruation, and the rights of all persons regardless of ability to receive health care. Target audience: Parents, caregivers, healthcare professionals and anyone who wants to learn more about this subject. Jane Lane, RN, BSN, University of Alabama at Birmingham Research Nurse Manager and Clinic Coordinator. Saturday, 4:15-5:00

Writing: Helping Everyone Get Started and Improve. In this presentation we will focus on how to provide all children with an assistive writing tool and writing experiences from Day #1. We will focus on core writing strategies and principles such as getting started when nothing has been tried previously or everything that was tried failed, supporting topic selection, responding to non-conventional writing, assessing growth in non-conventional writing, and when and how to teach skills. David Koppenhaver, PhD, Professor in the Department of Reading Education and Special Education (RESE) at Appalachian State University, Karen Erickson, PhD, David E. & Dolores (Dee) Yoder Distinguished Professor of Literacy and Disability Studies, Director, Center for Literacy & Disability Studies, University of North Carolina at Chapel Hill. Sunday, 10:45-11:45

“Your success and happiness lies in you. Resolve to keep happy, and your joy and you shall form an invincible host against difficulties.”
– Helen Keller
“The soul is healed by being with children”

– Fyodor Dostoevsky

2016 Keepsake Journal
Dear Lord,

Today, I once again bring my child to you. Please show me how to parent this precious gift that you have given me. Help me to be the best parent that I can be. I pray that Your Holy Spirit will teach me, Your wisdom will guide me, and Your love will move me. Most of all, Lord, I give this child to You. Please make her a servant after Your own heart.

In Jesus Name I pray,

AMEN

Dearest Isabel,

You have brought so much joy and love to our family that we could have ever imagined. Each day you share your contagious smile and happiness with us. We learn from you that the simplest of tasks is a blessing from God, not to be taken for granted. I want you to know that I am your voice but you are my heart.

I love you to the moon and back,

Mommy

My sweet angel Leila. You have shown me how to love deeper than I could have ever imagined possible. Thank you for that radiant smile that melts everyone’s heart and gives me energy to move forward. I’m honored to be your mommy and I hope I can make you proud.

Love you until the end of time and beyond!

Love,
Mommy, Nina and
daddy from above

“A very little key will open a very heavy door.”

– Charles Dickens

In honor of
Rachel Julia Flick

with love from
Grandma and Papa Solender
Our third family conference is dedicated to all the parents, caregivers, doctors, and scientists that work diligently to improve the lives of those affected by CDKL5 disorder. A special thank you to all the families that have hosted fundraisers, provided information for the database, taken their children to one of our CDKL5 Centers of Excellence, and volunteered their time and efforts to help our foundation thrive. We would also like to express our gratitude to the doctors, nurses, and coordinators committed to our clinics; because of you, we are learning ways to improve the quality of life for our kids! Your dedication and compassion are a comfort to us. We are grateful to the scientists working tirelessly in the labs as they search for treatments and a cure. We are honored to volunteer our time and service for such a wonderful group of people. As a team, we will learn and grow; TOGETHER we will be successful! We hope this conference empowers you to be the best possible advocate you can be!

Katheryn, Melissa, Karen, Amanda, Kristin, Kelly, Dustin
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TO ALL THE PARTICIPANTS, OLD & YOUNG...
TO THE SUPPORTERS, FUNDERS, FAMILY & FRIENDS...
WHETHER YOU TRAVELED BY PLANE, TRAIN OR AUTOMOBILE...

THANK YOU.
YOU ARE A WORLD CHANGER.
YOUR PARTICIPATION IN RETT SYNDROME RESEARCH HELPS PAVE A PATH, MAKING RETTLAND A BETTER AND BRIGHTER PLACE TO BE.

RETTLAND FOUNDATION

“Only those who care about you can hear you when you’re quiet.”

“You suppose you are the trouble. But you are the cure.
You suppose that you are the lock on the door. But you are the key that opens it.”

– Rumi
We dedicate this 32nd annual family conference to all individuals and foundations worldwide who STAND up for Rett syndrome and related disorders, especially our

BOARD OF DIRECTORS, FAMILY EMPOWERMENT BOARD, SCIENTIFIC ADVISORS, COLLABORATIVE ASSOCIATIONS AND FOUNDATIONS, RESEARCH INSTITUTES AND RESEARCHERS, STATE RESOURCE REPRESENTATIVES, EVENT CHAIRS & FUNDRAISERS, VOLUNTEERS, DONORS, SUPPORTERS, DOCTORS, NURSES, THERAPISTS, EDUCATORS, CELEBRITIES, POLICY MAKERS, FAMILIES, OUR EXCEPTIONAL CONFERENCE ATTENDEES, AND ESPECIALLY OUR CHILDREN WITH RETT SYNDROME

You motivate and inspire us.
You are our heroes and we remind you:

“When everything seems to be going against you, remember that the airplane takes off against the wind, not with it.”

—Henry Ford
Welcome to our first family conference!

This conference is a dream brought to life. A dream, that, almost four years ago was just a twinkle in our eyes, a silent hope that someday, maybe, just maybe, it would be real. Today, we welcome that new reality and wonder- what other dreams will come true? Perhaps a cure? We are honored to dream this dream with all of you, and cannot wait to make that a reality as well.

With Love,
Ileana, Heather, Stefanie, Tamra, Melanie, Jennifer, and Nicole