

**6th ALSTRÖM SYNDROME INTERNATIONAL FAMILY CONFERENCE,
MEDICAL RESEARCH CLINIC
AND
SCIENTIFIC SYMPOSIUM
JUNE 24 – 28, 2010
HELEN, GEORGIA USA**

THURSDAY, JUNE 24

06:30 - 08:30 BREAKFAST BUFFET
07:00 - 16:00 RESEARCH CLINIC ~ *Available children will be scheduled individually*
11:00 - 13:00 ASI BOARD MEETING
13:00 - 22:00 CONFERENCE REGISTRATION (Families, Volunteers, Translators, and Buddies Meet)
18:00 - 20:00 DUTCH TREAT (Pay your own) INFORMAL BUFFET DINNER
20:00 - 23:00 A-TEAM, PARENTS AND PROFESSIONALS NETWORKING AND RELAXING

FRIDAY, JUNE 25

06:30 - 08:30 BREAKFAST BUFFET
07:00 - 11:30 RESEARCH CLINIC ~ *Available children will be scheduled individually*
07:30 - 10:30 REGISTRATION
08:30 - 09:00 WELCOME AND ANNOUNCEMENTS
08:30 - 11:30 CAREFULLY SCHEDULED AND SUPERVISED ACTIVITIES FOR ALL CHILDREN
(Everything from shelter building to animal tracks to fishing to wilderness survival and scavenger hunts)
TOT TENDING FOR THOSE 5 AND UNDER – Expert (on-site) Supervision
MORNING SESSIONS FOR THE A-TEAM, PARENTS AND PROFESSIONALS
09:00 - 09:45 **How We Got Here...Milestones: *Jan D. Marshall***
09:45 - 10:30 **What It Means to Be Here...A Mother's Journey: *Sandra Hubbard-LeBlanc***
10:30 - 10:45 COFFEE BREAK
10:45 - 11:15 **Just Being Here...An Insider's View: *Shannon Caldwell***
11:15 - 11:30 CHILDREN RETURN FROM ACTIVITIES FOR LUNCH
11:30 - 13:00 LUNCH AND ANNOUNCEMENTS
13:00 - 17:00 AFTERNOON ACTIVITIES FOR CHILDREN AND *SPLIT* SESSIONS FOR PARENTS
13:00 - 14:00 **A) Hearing Issues for the Youngster**
B) Kidney Issues in the Adolescent and Adult
14:00 - 15:00 **A) Developmental, Cognitive, and Behavioral Issues for the Youngster**
B) Bladder Dysfunction: Investigation and Treatment for the Adolescent and Adult
15:00 - 15:15 COFFEE BREAK
15:15 - 16:15 **A) Education Issues and Effective Advocacy**
B) Beyond Diabetes: Other Endocrine Issues
16:15 - 17:15 **A) Heart Issues in the Infant and Youngster**
B) Heart Issues in the Adolescent and Adult
17:15 - 18:30 Free Time, Families Reunite with Children
Silent Auction Display
18:30 - 20:00 DINNER ~ Special Greetings and singalong
20:00 - 23:00 A-Team, Parents and Professionals Networking and Relaxing

SATURDAY, JUNE 26

06:30 - 08:30 BREAKFAST BUFFET
07:00 - 12:00 RESEARCH CLINIC ~ *Available children will be scheduled individually.*
08:30 - 11:30 CHILDREN, BUDDIES, AND A-TEAM ACTIVITIES
PATIENTS, PARENTS, AND PHYSICIANS SHARE
08:45 - 09:45 **Hyperphagia and Food Management Issues**
09:45 - 10:45 **Diabetes and Hyperinsulinemia**
10:45 - 11:00 COFFEE BREAK
11:00 - 12:00 **Helen Keller National Council**
12:00 - 13:30 BREAKOUT LUNCHEONS FOR PARENTS, FAMILIES and PROFESSIONALS
SPECIAL LUNCHEONS OFF-CAMPUS FOR A-TEAM, CHILDREN, SIBLINGS
13:30 - 17:30 AFTERNOON ACTIVITIES FOR CHILDREN AND SIBLINGS

13:30 – 1600 AFTERNOON SESSIONS FOR PARENTS
 13:30 - 14:30 **ASK THE A-TEAM** ~ An Unparalleled Opportunity For Parents To Seek Enlightenment And Guidance!
 14:30 – 17:00 **A) For Scientists Only: FROM BENCH TO BEDSIDE**
B) A-Team Only: COPING, INDEPENDENT LIVING, DREAMS AND FEARS
C) New and Younger Families Only: LIVING WITH ALSTRÖM SYNDROME
D) Older and “Veteran Families Only: LIVING WITH ALSTRÖM SYNDROME
E) Special Time for Those Who Have Lost a Child: SORROWS AND TREASURES
 17:00 - 18:30 COCKTAIL HOUR, LIVE MUSIC, AND SILENT AUCTION DISPLAYS
 18:30 - 21:00 BANQUET, ENTERTAINMENT, ADDRESSES AND SILENT AUCTION
 21:30 - 23:00 ENTERTAINMENT – DJ AND DANCING

SUNDAY, JUNE 27

06:30 - 08:30 BREAKFAST BUFFET
 07:00 - 11:30 RESEARCH CLINIC ~ *Available children will be scheduled individually.*
 08:30 - 11:30 MORNING ACTIVITIES FOR CHILDREN, BUDDIES, SIBLINGS
 08:30 - 11:30 **Assistive Technology Sessions for A-Team**
 08:30 - 11:30 MORNING SESSIONS FOR PARENTS AND PROFESSIONALS
 08:30 - 09:30 **Panel Discussion: Vision: Prognosis/Realities/Strategies/ Possibilities**
 09:30 - 10:15 **Panel Discussion: Genetic Testing ~ Options and Conundrums**
 10:15 - 10:30 COFFEE BREAK
 10:30 - 11:15 **Panel Discussion: Cultivating Success and Optimism in Our Children**
 11:15 – 12:00 **Panel Discussion: Sensory Deficits, Needs, and Resources**
 12:00 – 12:30 **Research Update – The Ciliopathies and Alström Syndrome**
 12:30 - 13:45 LUNCH
 13:30 - 14:00 BUSES DEPART FOR DOWNTOWN HELEN
 13:45 - 16:30 SHOPPING, SIGHTSEEING, HORSE AND BUGGY RIDES, ETC
 16:30 - 17:00 BUSES RETURN TO THE LODGE
 18:00 - 21:00 COOKOUT ~ In the woods of Unicoi State Park
 21:00 - 01:00 PARENTS, PROFESSIONALS AND A-TEAM NETWORKING AND RELAXING
 MOVIES, GAMES, AND MORE FOR CHILDREN AND SIBLINGS

MONDAY, JUNE 28

06:30 - 08:30 BUFFET BREAKFAST
 08:30 - 12:00 MORNING ACTIVITIES AND SESSIONS
 08:30 - 10:30 **Hands On Technology Session for the A-TEAM, Children and Teenagers**
 08:30 - 12:00 **Assistive Technology and Mentoring by the A-TEAM**
 08:30 - 12:00 **Curbside Consultations with Professionals ~ An Exceptional Opportunity for One-on-One Conversations!**
 11:00 - 14:30 **BAGGED LUNCH** (On Site or Take Away) and FAREWELLS



TRAVEL SAFELY AND BE WELL UNTIL WE MEET AGAIN