

**9th ALSTRÖM SYNDROME INTERNATIONAL FAMILY CONFERENCE
MEDICAL RESEARCH CLINIC
AND
SCIENTIFIC SYMPOSIUM
MAY 2 – 6, 2019
GALVESTON TEXAS USA**

WEDNESDAY, MAY 1 PRE-CONFERENCE ACTIVITIES

- 09:00 – 11:00 ASI DEPARTMENT HEAD MEETING [McArthur 7th Floor]
13:30 – 15:00 PRE-CON MEETING GALVEZ MANAGERS [McArthur 7th Floor]
18:00 – 20:00 DINNER ON YOUR OWN [On-site or Nearby Walkable Possibilities]
20:00 – 23:00 A-TEAM, PARENTS AND PROFESSIONALS NETWORKING AND RELAXING [The Carl Henry aka Galvez Bar and Grill]

THURSDAY, MAY 2 PRE-CONFERENCE ACTIVITIES/REGISTRATION/ORIENTATION

The following spaces will be available pretty much fulltime throughout the conference!

- ~ **Music Hall** – General Sessions
- ~ **West Parlor** – A-Team Cave: Let's Talk Tech! Vendors, displays, hands-on opportunities, and more.
- ~ **Pool** (SUPERVISION required!!)
- ~ **Game Room (Room 227)**
- ~ **Tot Room (Navigator)**

06:30 – 09:30 BREAKFAST [Galvez Bar and Grille or Area Restaurants]

07:30 – 08:30 ASI DEPARTMENT HEAD MEETING [McArthur]

09:00 – 22:00 **CONFERENCE REGISTRATION** (Families, Volunteers, and Buddies Meet) [West Promenade]

15:15 – 16:15 **SNAPSHOT OF WHAT TO EXPECT** (for new families) [East Parlor] Meet with Robin Marshall, Executive Director and Gina Denbow, Family Support Coordinator.

17:30 – 19:00 WELCOME RECEPTION [Veranda] Appetizers, beer and wine, cash bar.

19:00 – 21:00 DINNER-ON-OWN [GALVEZ or AREA RESTAURANTS] [SCIENTISTS are off-site]

20:00 – 23:00 A-TEAM, PARENTS AND PROFESSIONALS NETWORKING AND RELAXING [Promenade]

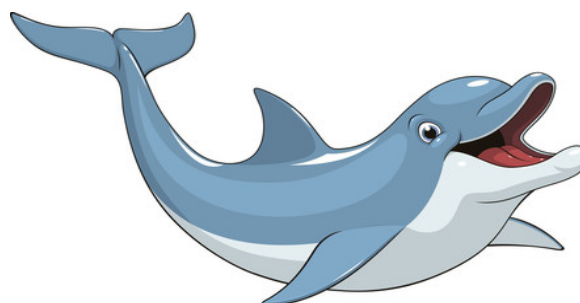
**08:30-20:00 SCIENTIFIC SESSIONS (SYMPOSIUM FOR PHYSICIANS
AND SCIENTISTS [SPACE CENTER HOUSTON])**

***Generously Supported with a Platinum Sponsorship from
Rhythm Pharmaceuticals***

**SCIENTIFIC SESSIONS: SYMPOSIUM FOR PHYSICIANS AND RESEARCHERS
SPACE CENTER HOUSTON
May 2, 2019**

- 08:30 – 08:45 WELCOME
*Clair Francomano, MD. Chair Scientific Advisory Board; Director,
Harvey Institute for Human Genetics, Greater Baltimore Medical Center*
- 08:45 – 09:15 ALSTROM SYNDROME: NATURAL HISTORY BASED ON A CLINIC COHORT
Antonie D. Kline, MD. Harvey Institute for Human Genetics, GBMC

- 09:15 – 09:45 IT'S TIME TO LISTEN: SCIENCE IS NOT THE ONLY PRIORITY FOR FAMILIES AND PATIENTS
Anne Nordstrom, MBA, PhD.
- 09:45 – 10:00 COFFEE BREAK
- 10:00 – 10:30 FIBROSIS in ALSTROM SYNDROME
Roderick Bronson, DVM. Harvard University
- 10:30 – 11:00 A NEW NEUROCOGNITIVE PHENOTYPE IN ALSTROM SINDROME
Francesca Dassie, MD. Department of Medicine (DIMED), University of Padua
- 11:00 – 11:30 EFFECT OF SETMELANOTIDE ON BODY WEIGHT AND HUNGER IN INDIVIDUALS WITH ALSTROM SYNDROME
Murray Stewart, MD. Rhythm Pharmaceuticals
- 11:30 – 12:00 THE LIPIDOPATHOLOGY OF ALSTROM SYNDROME
Vincent Marion, PhD. INSERM, Strasbourg, France
- 12:00 – 14:45 LUNCH, TRAM TOUR, and EXHIBITS
- 14:45 – 15:15 METABOLIC SYNDROME IN ALSTROM SYNDROME: IS IT THE FAT OR THE GENE THAT MATTERS?
Tarekegn Hiwot, MD. University Hospitals Birmingham NHS Foundation Trust
- 15:15 – 15:45 MYOCARDIAL FIBROSIS IN ALSTROM: THE END OR BEGINNING?
Richard Steeds, MD. University Hospitals Birmingham NHS Foundation Trust
- 15:45 – 16:15 PBI – 4050 IN SUBJECTS WITH ALSTROM SYNDROME
John Moran, MD. Prometic Life Sciences Inc. Laval, Québec, Canada
- 16:15 – 16:45 RESPIRATORY PROFILE IN ADULT ALSTROM PATIENTS
Shyam Medathil, MD. University Hospitals Birmingham NHS Foundation Trust
- 16:45 – 17:30 HEPATIC STIFFNESS EVALUATION USING SHEAR WAVE ELASTOGRAPHY IN ALSTRÖM SYNDROME
Pietro Maffei, MD, PhD. Department of Medicine (DIMED), University of Padua
- DINNER IN THE STARSHIP GALLERY GRACIOUSLY SPONSORED BY ALSTROM CANADA**
- 18:00 – 20:00 Cocktails, Hors d'oeuvres, and Dinner



FAMILY SESSIONS

FRIDAY, MAY 3 DAY 1

As noted above, supervised recreational space has been provided for the children. In addition, there will be carefully chaperoned and age- appropriate activities on Friday, Saturday, and Sunday, including off-campus trips to AREA attractions.

The following spaces will be available pretty much fulltime throughout the conference!

- ~ **Room 227** – Game Room for Youngsters (6 – 11)
- ~ **West Parlor** – Let’s Talk Tech! Vendors, displays, hands-on opportunities, and more.
- ~ **Pool (SUPERVISION required!!)**
- ~ **Navigation** - Tot Room (1 – 5)

06:30 – 08:00 BREAKFAST BUFFET [**Veranda**]

06:30 – 10:00 REGISTRATION FOR LATE COMERS [**West Promenade**] 08:30 – 08:45

08:00 - 08:30 Children 1 - 5 (Impacted and Sibs) depart for the Galveston Children’s Museum
Children 6 – 11(Impacted and Sibs) depart for Galveston Children’s Museum
Children 12 – 17 (Impacted) depart for Seaport and Pleasure Pier
Children 12 – 17 (Siblings) depart for Space Center Houston
A-Team – Remains on Campus for morning presentations

13:30 – 17:30 A-Team – Departs for Moody Gardens

08:30 – 08:45 WELCOME AND INTRODUCTIONS [**Music Hall**] **Robin Marshall, Executive Director**

08:45 – 09:15 EFFECT OF SETMELANOTIDE ON BODY WEIGHT AND HUNGER IN INDIVIDUALS WITH ALSTROM SYNDROME **Murray Stewart, MD. Rhythm Pharmaceuticals**

09:15 – 10:00 PERSONAL PERSPECTIVES ON THE ROLE AND IMPORTANCE OF ASSISTIVE TECHNOLOGY: A PANEL OF A-TEAM PROS. **Chair, Doula Jarboe; Jamie Seeger; Alex Griffiths-Rayson; Shannon Caldwell; Christopher Schiafone; Brandon Schiafone**

10:00 – 10:15 **COFFEE BREAK**

10:15 – 10:45 COMMON ASSISTIVE DEVICES AND MORE. **Raul and Stacie Gallegos. RGA Tech Solutions.**

10:45 - 11:15 TECHNOLOGY FOR LIFE. **Marco Gregnanin, CEO ITEX, Rome, Italy**

11:15 – 12:00 CHALLENGES AND NEEDS FACING ALSTROM STUDENTS. **Christopher and Brandon Schiafone, Toronto, Canada**

12:00 – 13:00 **LUNCH and ANNOUNCEMENTS [Terrace and Veranda]**

13:00 – 13:45 GENETICS OF ALSTROM SYNDROME 101. **Antonie D. Kline, M.D. Director of Pediatric Genetics Harvey Institute for Human Genetics, Greater Baltimore Medical Center, Baltimore, MD**

13:45 – 14:30 SHORT COURSE OF ENDOCRINOLOGY & METABOLISM IN ALSTRÖM SYNDROME
Pietro Maffei, MD, PhD, University of Padua, Padua, Italy

- 14:30 – 15:15 MYOCARDIAL FIBROSIS IN ALSTROM: THE END OR BEGINNING? **Richard Steeds, MD. University Hospitals Birmingham NHS Foundation Trust**
- 15:15 – 15:30 **BREAK**
- 15:30 – 16:15 PBI – 4050 IN SUBJECTS WITH ALSTROM SYNDROME. **John Moran, MD. Prometic Life Sciences Inc. Laval, Québec, Canada**
- 16:15 – 17:00 RESPIRATORY PROFILE IN ADULT ALSTROM PATIENTS
Shyam Madathil, PhD . University Hospitals Birmingham NHS Foundation Trust
- 18:30 – 20:30 BUFFET DINNER (A Southwestern extravaganza to suit every taste!)
Keynote Speaker: Mr. Shannon Caldwell, A-Team Leader and ASI Ambassador: Making the Most of Life!
- 20:30 – 23:00 NETWORKING AND RELAXING

SATURDAY, MAY 4 DAY 2

- 06:30 – 08:00 BREAKFAST BUFFET [**Veranda**]
- 07:00 – 08:00 ASI DEPARTMENT HEAD MEETING [**MacArthur**]
- 08:00 – 08:30 Children 1 - 5 (Impacted and Sibs) report to Playroom and then depart for Moody Gardens
Children 6 – 17 (Impacted and Sibs) depart for Space Center Houston.
Children 12 – 17 (Impacted) depart for Space Center Houston
Children 12 -17 (Siblings) depart for Moody Gardens via the Seaport
A-Team – Departs for Houston Space Center
- 08:30 – 09:15 METABOLIC SYNDROME IN ALSTROM SYNDROME: IS IT THE FAT OR THE GENE THAT MATTERS? **Tarekegn Hiwot, MD. University Hospitals Birmingham NHS Foundation Trust**
- 09:15 – 10:00 OPTIMIZING NUTRITION FOR OPTIMAL HEALTH. **Clair Francomano, MD. Chair Scientific Advisory Board; Director, Harvey Institute for Human Genetics, Greater Baltimore Medical Center**
- 10:00 - - 10:45 FUNCTIONAL AND HOLISTIC MEDICINE IN GENETIC DISEASES/ALSTROM SYNDROME
Selma Duzenli, MD, PhD. Abant Izzet Baysal University, Bolu, Turkey. ASI Board.
- 10:45 – 11:00 **COFFEE BREAK**
- 11:00 – 12:00 WE TALKED, WE LISTENED, WHAT NEXT? A CALL TO ACTION! **Anne Nordstrom MBA, PhD**
- 12:00 – 13:00 LUNCH and ANNOUNCEMENTS
- 13:00 – 14:30 ASTROM SYNDROME UK – THE JOURNEY SO FAR, **Alex Griffiths Rayson (ASUK Trustee) and Ann Chivers (ASUK Chief Executive)**
- 14:30 – 15:00 **COFFEE BREAK [FIRST LOOK AT SILENT AUCTION ITEMS - Peacock Alley]**
- 15:00 – 16:00 ASK THE A-TEAM. **Moderated by Clair Francomano.** A rare opportunity to gain insights into the world your children inhabit. There are no dumb questions!
- 16:00 – 16:30 Wrap up and Preview of Sunday's Activities
- 17:30 – 18:30 COCKTAILS AND CASH BAR [**West Promenade**]

17:30 – 21:00 AUCTION BIDDING WARS [**Peacock Alley**]. **AUCTION CLOSSES AT 21:00.**

18:30 – 23:00 DINNER AND DANCING TO DJ ROCK N' ROBIN AND PHOTO BOOTH. [**Veranda and Terrace Ballroom**] **Keynote Address: Jamie Seeger, Scion of a Founding Family.**
Wisdom Down Through the Ages.

SUNDAY, MAY 5 DAY 3

07:00 – 09:00 BREAKFAST BUFFET [**Terrace**]

09:00 – 11:30 CHELSEY'S OLYMPICS [**Front Yard**] For Children 4 – 12. **Shelly Marshall, President, Alstrom Olympic Committee, Burleson, TX.** Fun and games with medals for all!

09:00 – 11:30 JUST for SIBLINGS [**East Parlor**]. For brothers and sisters aged 13 and up. Adult Sibs strongly encouraged to attend! A unique opportunity to explore what it means to be the sibling of someone with Alstrom Syndrome.

09:00 – 11:30 TECH TALK AND MORE WITH THE A-TEAM [**West Parlor**] Especially for parents of younger children and adolescents. Explore assistive technology, both hands-on and theoretical, with those in the know. OR, grab a corner and have a quieter conversation regarding guidance on any number of topics. Most A-Teamers are eager to share their wisdom, and most adolescents are eager to ask unique questions of concern.

12:00 – 17:00 LUNCH ON YOUR OWN IN **FRIEDLY GALVESTON**. Stay close to home or head for The Strand, Historic Galveston's Center. Tons of fun! And....Open Carry – not guns, but alcohol! NOTE: Shuttles will be available to take to The Strand from 12:00 – 13:30 with returns to The Galvez from 15:00 – 16:30.

18:00 – 20:00 OUTDOOR BBQ TEXAS STYLE

20:00 – 23:00 RELAX, NETWORK, USE THE POOL, STROLL THE BOULEVARD!

MONDAY, MAY 6 DAY 4

06:30 – 09:30 BREAKFAST BUFFET [Terrace]

09:00 – 11:00 GENERAL MEETING FOR FAMILIES: MEETING YOUR NEEDS/MEETING THOSE OF ASI

11:00 - 12:00 CHECK OUT AND FAREWELLS

Travel well and safely until we meet again!

