

EBF3 HADDS International Conference

KNOWLEDGE | COMMUNITY | RESEARCH | RESOURCES

Texas Children's Hospital
Jan & Dan Duncan
Neurological Research Institute

July 21-23, 2022

HOUSTON, TX



Welcome to Houston!

The EBF3 HADDS Foundation welcomes you to the 2022 HADDS International Conference! We hope the next few days will provide you with new knowledge about HADDS, connect you with other families in our community, and help you feel energized and hopeful about the exciting developments in HADDS research!

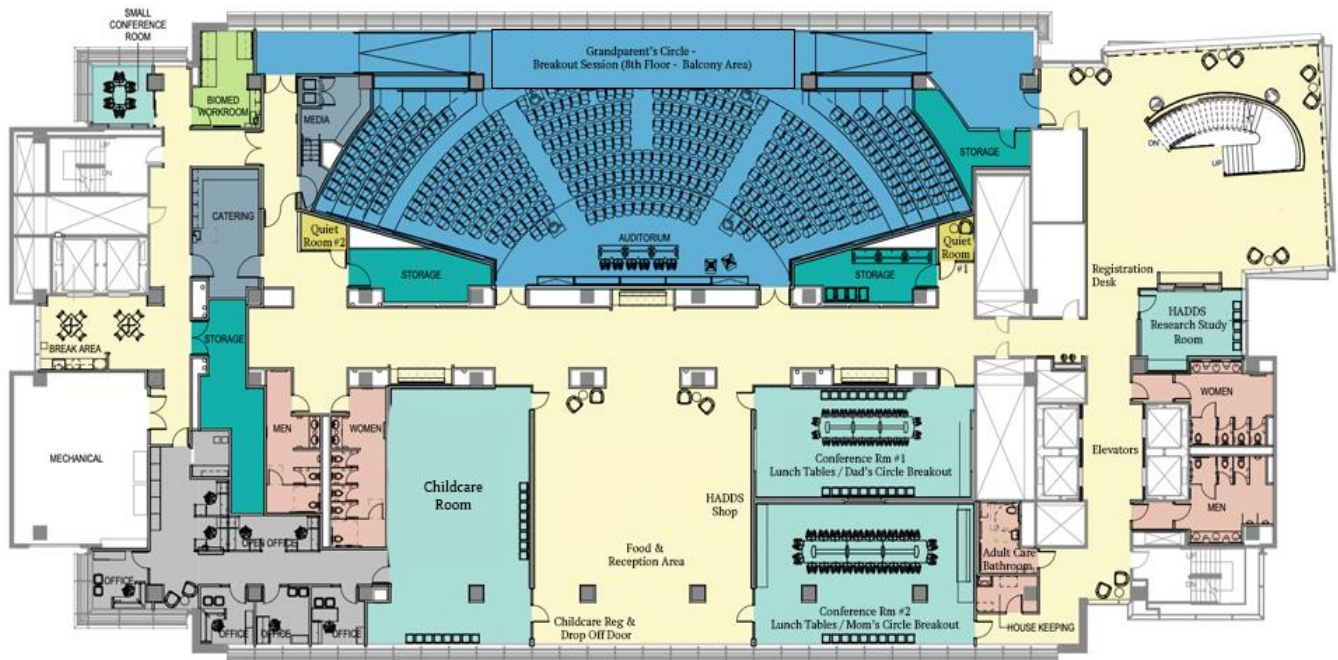
We have nearly 60 families and nearly 200 people joining from seven countries, both in person and virtually. The next few days will be informative, fun, emotional and busy! We encourage everyone to take advantage of the short time together and ask questions. Our next conference in Houston won't be until July 2024.

Please let us know if you have questions/concerns about the conference or about exploring Houston—we want to ensure you have a wonderful time! Our email is info@HADDS.org or you can text board members Ashley LeMaire (832-331-4166) / Mark LeMaire (228-596-4026) who are locals to Houston.

EBF3 HADDS Foundation,
Board of Directors



Ting Tsung and Wei Fong Chao Foundation Conference Center Map



Conference Center Rules



Please be respectful of other attendees by being quiet and silencing cell phones during the conference sessions.



Please no eating or drinking in the Auditorium (applies to both upper and lower levels).



We have several attendees with peanut allergies. Please do not eat or open any food that has peanuts in NRI.



Attendees should be vaccinated, and masks are required inside NRI (Auditorium/Lab/Break Out Rooms, etc.)



Please no audio recordings and/or filming of the conference sessions.



If you need a mental break, we have a designated quiet room located on the 7th floor outside the Auditorium or have an upper balcony for more space and seating options.



The NRI & Texas Children's Hospital buildings are part of a smoke-free campus.

Additional Questions?

Visit the registration desk or ask one of the HADDs Board Members. You can also email info@hadds.org. We will be checking email throughout the conference.

Conference Schedule

Thursday, July 21, 2022

Time	Length	Topic	Speaker
8:30-9:30 am		Childcare Registration & Breakfast	
9:30-9:45 am	15 minutes	Welcome & Announcements	The EBF3 HADDS Foundation Board
9:45-10:30 am	45 minutes	Genetics 101	Hayley Streff, MS, CGC
10 Minute Break			
10:40-11:40 am	60 minutes	The Neurological Impact of HADDS	Dr. Hsiao-Tuan Chao
11:40-12:40 pm	60 minutes	Research Gift / Group Photo / Lunch	
12:40-1:25 pm	45 minutes	The Psychopharmacology of Comorbid Behavioral Disorders/Symptoms	Dr. Christopher J. McDougle
10 Minute Break			
1:25-2:10 pm	45 minutes	Addressing Common Questions About ASD	Dr. Robin P. Kochel
10 Minute Break			
2:20-3:05 pm	45 minutes	Non-neurological & Genetic Findings of HADDS	Dr. Michael Wangler
10 Minute Break			
3:15-4:15 pm	60 minutes	Potential Urological Implications of EBF3 HADDS	Dr. Irina Stanasel
Sessions Conclude / Childcare Pickup / Pizza Reception in NRI Lobby Until 5:30 PM			
4:00-5:30 pm		Meet & Greets - NRI	Dr. Hsiao-Tuan Chao & Dr. Michael Wangler
6:00-9:00 pm	3 Hours	Hilton Medical Center Pool Party - Bring Your Leis!	

Friday, July 22, 2022

Clinic Day / Research Study Participation / Chao Lab Tours

Saturday, July 23, 2022

Time	Length	Topic	Speaker
9:00-9:30 am		Childcare Drop Off & Breakfast	
9:30-10:15 am	45 minutes	Parental Mental Health: Whose Oxygen Mask Goes On First?	Dr. Elisabeth Netherton & Dr. Jessica Rohr
10:15-10:45 am	30 minutes	The Greatest Club You Never Wanted To Join: Testimonial & Advocacy	Ashley Kress
10 Minute Break			
10:55-11:40 am	45 minutes	Supporting Language Development In Play & Learning Environments	Alana Ladd
11:40-12:25 pm	45 minutes	Sleep Disorders	Dr. Mary Rose
12:25-1:15 pm	50 minutes	Lunch & Foundation Update	
1:15-2:15 pm	60 minutes	Future Directions & Panel Discussion	Dr. Hsiao-Tuan Chao & Dr. Michael Wangler
10 Minute Break			
2:25-3:10 pm	45 minutes	Special Needs Planning	Kimberly Hegwood, J.D.
3:15-4:15 pm	60 minutes	Dad / Mom / Grandparent / Virtual Circles	Conference Rooms, Balcony & Zoom
Conference Sessions Conclude			
3:45-5:00 pm		Meet & Greets (Hotel- Travis A (8th Floor)	Dr. Hsiao-Tuan Chao & Dr. Michael Wangler



Speaker Bios

EBF3 HADDS



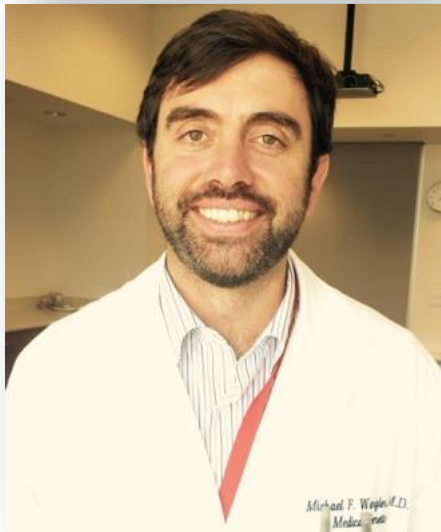
Hsiao-Tuan Chao, M.D., Ph.D.
**Assistant Professor of Molecular and Human
Genetics, Pediatrics, and Neuroscience Baylor
College of Medicine Investigator,
Jan and Dan Duncan Neurological Research
Institute, Texas Children's Hospital**

Dr. Tuan Chao is a member of the faculty at the Jan and Dan Duncan Neurological Research Institute (NRI) at Texas Children's Hospital (TCH) and Baylor College of Medicine (BCM). She received her M.D. and Ph.D. degrees from BCM as a Medical Scientist Training Program McNair Scholar,

supported by the McNair Medical Institute of The Robert and Janice McNair Foundation.

She obtained her Ph.D. in Neuroscience from the laboratories of Dr. Huda Y. Zoghbi and Dr. Christian Rosenmund, where she explored the role of excitatory and inhibitory neuronal dysfunction in Rett syndrome. Following her doctoral training, Dr. Chao completed a child neurology residency at BCM and TCH. During her residency, she pursued postdoctoral training in the laboratory of Dr. Hugo J. Bellen, where she studied transcriptional dysregulation in neurodevelopmental disorders. Her postdoctoral work led to the recognition of the EBF3-related Hypotonia, Ataxia, and Delayed Development Syndrome.

Researchers



Michael Wangler, M.D.

Assistant Professor

**Department of Molecular and Human Genetics
Baylor College of Medicine**

Michael Wangler completed his M.D. at Baylor College of Medicine in 2006 and completed Pediatric Residency at Texas Children's Hospital in 2009. He is board certified in Pediatrics and Medical Genetics. He is an Assistant Professor and physician scientist at the Jan and Dan Duncan Neurological Research Institute and in the Department of Molecular Human Genetics at Baylor College of Medicine.

His research interests include rare and undiagnosed disease, and using genomics in medicine. He is an expert in HADDs syndrome as well as peroxisomal disorders, Xia-Gibbs syndrome, and genetic brain disorders.

(Remaining Speakers are in Alpha Order)



Kimberly Hegwood, J.D.

Attorney at Law
Hegwood Law Group

Kim Hegwood is an Elder Law and Estate Planning Attorney based in Houston, Texas. Kim started her firm in 1998 so she could practice law her way – with a focus on family.

Hegwood Law Group focuses exclusively on Elder Law, Asset Protection, Estate Planning, Medicaid Crisis Planning, Probate, and Guardianship. Kim is passionate about educating her clients, helping them choose legal strategies that will achieve their goals with security and dignity.

As a mother of three, Kim enjoys spending most of her free time with her children and grandchildren when she is not volunteering at one of her favorite charities.



Robin Kochel, Ph.D.

Research Psychologist
Baylor College of Medicine / Texas Children's Hospital

Robin Kochel, Ph.D., is a research psychologist at Baylor College of Medicine and Texas Children's Hospital. She received master's degrees in Child & Family Studies and Clinical Investigation from The University of Tennessee, Knoxville, and Baylor College of Medicine, respectively, and her Ph.D. in Developmental Psychology from Virginia Commonwealth University. Her expertise is in the study of children with autism spectrum disorder (ASD). Dr. Kochel's greatest contribution to the field has been

through team-science projects conducted with other researchers across the United States. This work has led to important discoveries about the genetic causes of ASD. Because of this, Dr. Kochel was recently named as one of the most collaborative autism researchers in the past decade.

Research Narrative

Dr. Kochel's research mainly focuses on individuals with autism spectrum disorder, or ASD. ASD is a condition of the brain that affects how people learn, behave, and interact with others. Dr. Kochel works with affected children and their families to learn more about causes of ASD, how to detect ASD at earlier ages, and how parents' beliefs about ASD affect their decisions about health practices, such as whether to vaccinate their children or which treatments to use.



Ashley Kress

Parent Advocate
Director of Advancement
The Rise School of Houston

Ashley Kress, a Houston native, is the Director of Advancement at The Rise School of Houston, but first she is a mother and wife. Ashley and her husband Hugh Kress, an intellectual property attorney, are the proud parents of three children, Miller, Blakeley and Byron.

Miller, their oldest is 25 and a pediatric nurse living in New York. Their middle child Blakeley, is 23 and a graduate of the Clemson LIFE program, now living independently in South Carolina. Their youngest Byron, 22, is a cyber-security expert living in Baltimore, Maryland.



Alana Ladd

Educator

Alana has over 20 years' experience as an educator in Inclusive Education. She is from Alberta, Canada and holds an undergraduate degree in Elementary Education from the University of Alberta and a master's degree in educational psychology from the University of Victoria.

Alana has spent most of her career in Early Childhood Settings working both as a Teacher and Teacher Consultant. Alana spent most of her career working for Edmonton Public Schools. In her early teaching days, she taught children with behavior and emotional challenges in an elementary setting, but has spent the majority of her teaching career working in inclusive preschool settings supporting children with different abilities. She also has experience facilitating inclusion as a Teacher Consultant with Edmonton Public Schools.

Alana moved to Houston in 2015 and until recently worked as a lead teacher at The Rise School of Houston.



Christopher McDougle, M.D.

**Director, Lurie Center for Autism
Professor of Psychiatry and Pediatrics,
Massachusetts General Hospital and MassGeneral
Hospital for Children; Nancy Lurie Marks
Professor in the Field of Autism, Harvard Medical
School**

Dr. McDougle received a B.A. in chemistry from Valparaiso University in 1981 (with Highest Distinction) and an M.D. from Indiana University School of Medicine in 1986 (with Highest Distinction). He subsequently completed a residency in psychiatry at Yale University School of Medicine (1990) and a fellowship in child and adolescent psychiatry at the Yale Child Study Center (1995). After seven years on the faculty at Yale, Dr. McDougle joined the Indiana University School of Medicine (IUSM) in 1997 as the Raymond E. Houk Professor of Psychiatry and Director of the Section of Child and Adolescent Psychiatry. In September of 2000, Dr. McDougle was named the Albert Eugene Sterne Professor of Psychiatry and Chairman of the Department of Psychiatry at the IUSM. He continued as Director of the Section of Child and Adolescent Psychiatry, as well. In the fall of 2011, Dr. McDougle became the Director of the Lurie Center for Autism and the Nancy Lurie Marks Professor in the Field of Autism at Harvard Medical School.

Dr. McDougle is an internationally recognized expert in the neurobiology and neuro-psychopharmacology of childhood-onset neuropsychiatric disorders including autism spectrum disorder. His research interests also include the etiology and pathophysiology of syndromes associated with intellectual disability.

Dr. McDougle has been awarded two Young Investigator Awards from the National Alliance for Research on Schizophrenia and Depression (NARSAD), an Independent Investigator Award from NARSAD, a grant from the Theodore and Vada Stanley Research Foundation, a Research Unit on Pediatric Psychopharmacology (RUPP) contract, a RUPP-Psychosocial Intervention (PI) grant and additional research grants from the National Institute of Mental Health for the study of autism spectrum and related disorders.

Dr. McDougle was elected to the American College of Neuropsychopharmacology in 1995. He was twice chosen as Teacher of the Year by the Yale Psychiatry Residents. In 2002, Dr. McDougle was selected as a recipient of the 12th Annual Nancy C.A. Roeske, M.D. Certificate of Recognition for Excellence in Medical Student Education from the American Psychiatric Association, and in 2007 he was selected as a recipient of the Annual Irma Bland Award for Excellence in Teaching Residents, also by the American Psychiatric Association. Dr. McDougle was awarded the Frank J. Menolascino Award for Psychiatric Services for Persons with Mental Retardation/Developmental Disabilities from the American Psychiatric Association in 2009. He received the George Tarjan Award for Contributions in Developmental Disabilities from the American Academy of Child and Adolescent Psychiatry in 2012. In 2003, he was appointed Associate Editor of the Journal of Autism and Developmental Disorders.



Elisabeth Netherton, M.D.

**Psychiatrist
Regional Medical Director
Texas at Mindpath Health**

Dr. Elisabeth Netherton, MD is a board-certified Psychiatrist whose clinical work focuses on mental health, motherhood, and personality disorders. She received her medical degree from the University of Texas Health Science Center and completed residency at Baylor College of Medicine. She also has a certificate in Children and Health.

Dr. Netherton focuses on mental health and personality disorders across the lifespan, treating bipolar, anxiety, phobias, depression (Psychosis, Pregnancy, Suicidality), impulse control, anger, OCD and personality disorders. Dr. Netherton wants her patients to feel empowered and consider medication as a potential tool to improve overall wellness.



Jessica Rohr, Ph.D., ABPP

**Psychologist
Director, Women's Mental Health
Houston Methodist**

Dr. Rohr is a clinical psychologist, with an expertise in evidence-based practice. She received her doctorate degree from the University of Kentucky and was an intern and completed her post doctorate work at the Michael E. DeBakey Veterans Affairs Medical Center here in Houston.

Dr. Rohr is committed to the treatment and research of women's health issues, especially maternal mental health. Under her research and leadership, she has facilitated performance improvement needs, designed relevant cutting-edge programs and utilized consultation and process-oriented feedback to guide behavior change.



Mary Rose, PsyD, DBSM, CBSM
Psychologist, Menninger Clinic
Associate Professor, Baylor College of Medicine

Dr. Mary Rose is a staff psychologist with Menninger's Sleep Medicine Service. Dr. Rose completed a post-doctoral fellowship at the University of Texas Medical Branch in Galveston. She earned her doctorate from Virginia Consortium Program in Clinical Psychology, and her bachelor's degree from Hampshire College. In addition to sleep medicine, she has special expertise in health psychology, dementia, and caregiver's issues.

With more than 20 years of experience, Dr. Rose has given numerous local, regional, and national presentations related to sleep. Her research has also been published in such peer-reviewed journals such as Behavioral Sleep Medicine, Perioperative Management of Obstructive Sleep Apnea, Depression and Anxiety in Patients with Chronic Respiratory Diseases and Maternal and Child Health Journal. In addition, she has contributed to book chapters, including in Principles and Practice of Fatigue Management: Improving Workplace Safety. She is the president of the Southern Sleep Society and is a member of the Texas Psychological Association, Behavioral Sleep Medicine Society and Sleep Research Society.

In her free time, Dr. Rose pursues her passions for paleontology and conservation. She and her family love visiting the Houston Museum of Natural Science and the Houston Zoo.



Irina Stanasel, M.D.
Pediatric Urologist, Children's HealthSM
Assistant Professor of Urology
UT Southwestern Medical School

Irina Stanasel provides care for children of all ages who have a variety of urologic disorders. She received her medical degree from Baylor College of Medicine in Houston, Texas and completed her residency in urology at Wake Forest University Baptist Medical Center. She completed a pediatric urology fellowship at Texas Children's Hospital in Houston.

Her specialties include fetal urology, bladder bowel dysfunction, complex hypospadias repair, prune belly syndrome and quality improvement in pediatric urology.

In addition to her medical degree, Dr. Stanasel holds a chemical engineering degree from the University of Texas, Austin. She also spent two years as a faculty member at the University of New Mexico working with underserved populations.



Hayley Streff, MS, CGC

Certified Genetic Counselor, Texas Children's Hospital

Haley Streff is a certified genetic counselor at Texas Children's Hospital and Baylor College of Medicine. She completed her master's degree in genetic counseling at the University of Texas Health Sciences Center in Houston. She sees patients in the outpatient genetics clinics and multi-disciplinary craniofacial clinics at Texas Children's Hospital. She also works on genetic test utilization at Texas Children's Hospital and is a clinical supervisor for the Baylor genetic counseling program.

Haley enjoys participating in outreach and education in the rare disease community and she serves on the board of directors and multiple committees for various genetic and family support groups.

Lab Tours & Meet and Greet

Lab Tour Signup

The Chao “HADDs” Lab tours are on a first come, first serve basis. The tour signup sheet can be found at the registration desk. The tours will be on Friday at NRI. Please meet in the staircase lobby area near the registration area/elevators on the **7th Floor** next to the Lab Tour signage. Once everyone has arrived, the research team/tour guide will take you to the lab and allow you to ask questions about the research and space.

Group Size and Restrictions: The max size for a group is 10 people (6 adults, 4 kids).

Children must be 5 years and older to tour the lab.

Masks and vaccination are required.

Lab Tour Times

Tour #	Day	Time	Meet Location
1	Thursday	2:15 PM - 3:00 PM	Conference Registration Area
2	Thursday	3:00 PM – 3:45 PM	Conference Registration Area
3	Thursday	3:45 PM – 4:30 PM	Conference Registration Area
4	Thursday	4:30 PM – 5:15 PM	Conference Registration Area
5	Friday	8:30 AM – 9:15 AM	Conference Registration Area
6	Friday	9:15 AM – 10:00 AM	Conference Registration Area
7	Friday	10:00 AM – 10:45 AM	Conference Registration Area
8	Friday	10:45 AM – 11:30 AM	Conference Registration Area

Photo Waivers

We will have photographers from Texas Children’s Hospital/NRI and the Foundation on Thursday (and possibly Saturday). They will be taking photos of the event. If you do not wish to have your photo shared with attendees and/or in an article, please be sure to note on your photo waiver at registration. We will have a Research Gift ceremony and a large group photo just before lunch on Thursday, so please be sure to look sharp and rock your HADDs Plaid!

Upcoming Events!



Calling All Advocates!

Want To Help Further the Cause?
Join Our Board of Directors!

Application Due:

August 21, 2022

To Apply, visit: <https://www.hadds.org/bod-application>



HADDS *In Motion*

Race Season Begins: September 11 –
October 31, 2022



**Mark Your Calendars
The Next Social Circles Are:**

Sunday, September 11, 2022 at 3 PM CST

Saturday, November 5, 2022 at 7 PM CST



Directions & Local Attractions

Important Addresses

Jan and Dan Duncan Neurological Research Institute (NRI)

1250 Moursund St.
Houston, TX 77030

**(Conference Center
Auditorium is located
on the 7th Floor)**

The NRI is too far to walk in the Houston July heat from the hotel. Take the Hilton shuttle, Uber/Lyft or a car and park at the NRI, which is in the medical center. If you take the shuttle, allow yourself plenty of time before your scheduled conference sessions or lab tour time.

Please contact Ashley LeMaire (832-331-4166) or Mark LeMaire (228-596-4026) for directions or assistance if you get lost.

Parking: Visitor parking is available at the following locations:

Texas Medical Center Garage 6: 1329 Moursund St.
Texas Medical Center Garage 15: 6550 Bertner Ave.
Texas Medical Center Garage 2: 1151 E. Holcombe Blvd.

2-4 Hours	\$10
4-24 Hours	\$13
Lost Ticket	\$25

Parking Rates

For additional information on visitor parking, please visit [Texas Medical Center - Visitor Parking](#).

Blue Bird / HADDS Clinic

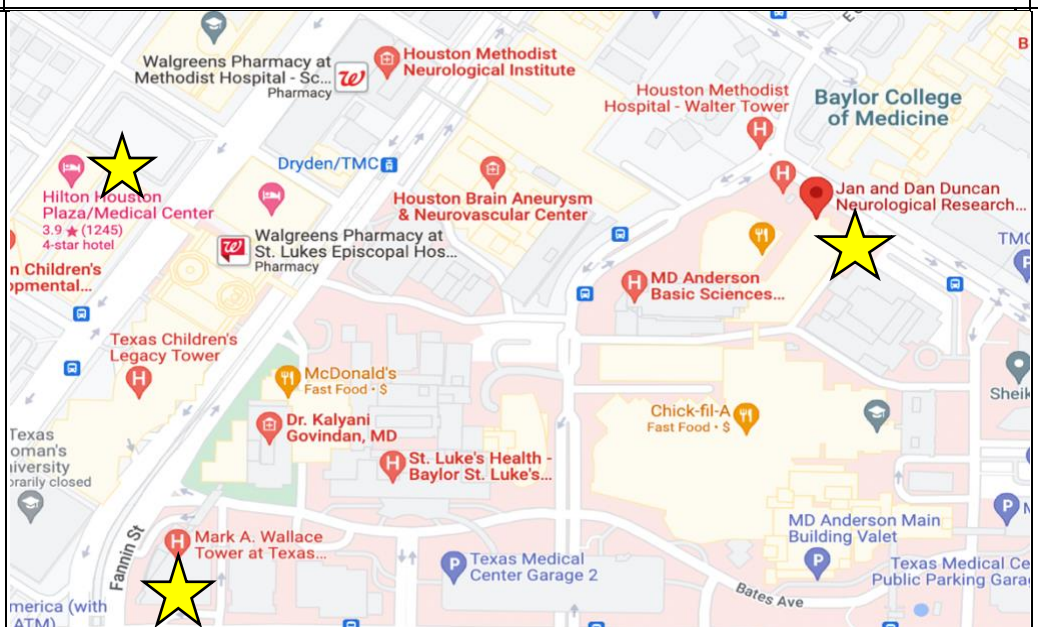
Mark Wallace Tower
Texas Children's Hospital
(Neurology)
6701 Fannin St.
Houston, TX 77030
+1 (832) 822-5046

The clinic is approximately a 10-minute walk from the hotel to the Blue Bird Neurology Clinic. From the hotel, exit the Hilton lobby and take a left towards Southgate Drive. Head southwest on Travis St toward Southgate Blvd. Then turn right toward Fannin St. Next turn left onto Holcombe Blvd and continue walking until you see the Mark A. Wallace Tower at Texas Children's Hospital.

Please contact Ashley LeMaire (832-331-4166) or Mark LeMaire (228-596-4026) for directions or assistance if you get lost.

Hilton Houston Plaza/Medical Center

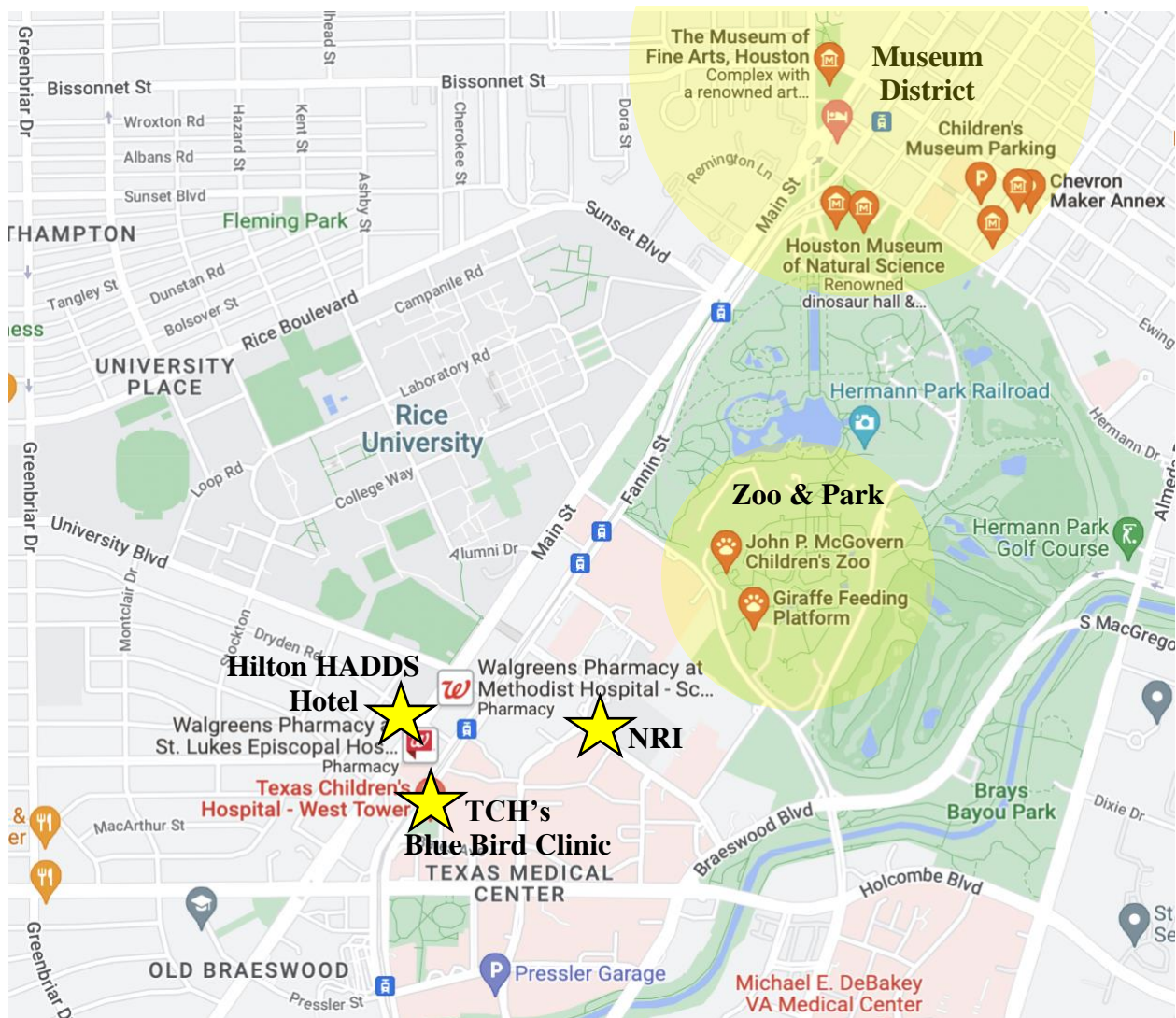
6633 Travis St., Houston,
TX 77030
+1 (713) 313-4000



Need Plans for Friday?

Try A Few Local Attractions Near the Medical Center

(In Hotel's Shuttle Route too!)



Museums:

Children's Museum
Museum of Fine Art
Natural Science Museum

Zoo/Parks:

Houston Zoo
Hermann Park
TCH's Playground

Other Attractions

(Outside of Shuttle Route)
NASA Space Center
Downtown Aquarium

Friday will be filled with individual appointments in the clinic (TCH's Blue Bird Neurology Clinic), research appointments (Medical Center Area), as well as lab tours at NRI. This is a workday and traffic may be unpredictable, so please keep that in mind as you venture around town.

Thank you

Thank you to the Jan and Dan Duncan Neurological Research Institute and Texas Children's Hospital, their staff and Dr. Chao, our sponsor, for allowing us to use the conference center facilities. The space fosters learning, community and is incredible!

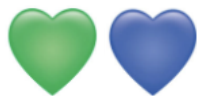
Thank you to our phenomenal speakers for preparing and sharing lectures for the betterment of our community.

Thank you to Dr. Chao, Dr. Wangler and the research team! It is rare to have opportunities to connect, tour/see the research and have the chance to ask questions directly to the individuals conducting the research. We are fortunate to have such a robust research team supporting our rare community – we are grateful for your work!

Thank you to our volunteers! We have volunteers from TCH/NRI/Baylor as well as family and friends who have donated their time to allow attendees to immerse themselves in the experience. Thank you!

Thank you to our Community! This conference wouldn't be possible without the gifts and fundraising of our HADDS supporters. We may be small, but we are certainly mighty! Look at what we can accomplish out of love and the pursuit of knowledge!

Lastly, thank you to the EBF3 HADDS Board of Directors! This group has powered through a crazy 2.5 years of COVID, to serve our community by organizing this conference, supporting the research, creating, and disseminating information and creating other community engagement opportunities for our HADDS family near and far. Their sacrifice of time, resources, and talent is priceless!



Until Next Time Friends...Safe Travels!