

## 2024 FAMILY CONFERENCE FAQ'S

**WHO:** OUR GLOBAL FAMILY – 113 FAMILIES FROM 14 REGIONS ARE PLANNING TO ATTEND!

**WHAT:** 2024 JORDAN'S GUARDIAN ANGELS FAMILY CONFERENCE

**WHEN:** JULY 12/13, 2024

**WHERE:** BOSTON, MASSACHUSETTS, USA – BOSTON MARRIOTT COPLEY PLACE 110 HUNTINGTON AVE

**WHY:** A WEEKEND FULL OF INFORMATION, RESEARCH GATHERING, JOY, LAUGHTER AND FUN!

**LINK TO AGENDA:** [HTTPS://JORDANSGUARDIANANGELS.ORG/EVENTS/](https://jordansguardianangels.org/events/)

**LINK TO PODCASTS:** [HTTPS://YOUTU.BE/B87EOAbWUTw](https://youtu.be/B87EOAbWUTw) [HTTPS://YOUTU.BE/wRFmHBEP02Q](https://youtu.be/wRFmHBEP02Q)

**LINK TO HOTEL TOUR:** [HTTPS://VISITINGMEDIA.COM/TT8/?TTID=BOSTON-MARRIOTT-COPLEY-PLACE#/360?GROUP=O&TOUR=O&C13RL3=1&HA17=1](https://visitingmedia.com/tt8/?ttid=boston-marrriott-copley-place#/360?group=O&tour=O&c13RL3=1&HA17=1)

### **WHAT'S ON THE AGENDA?**

FRIDAY AND SATURDAY ARE 2 FULL DAYS OF CONFERENCE ACTIVITY. YOU WILL GET UPDATES ON THE FOUNDATION, JORDAN'S SYNDROME RESEARCH, CLINICAL TRIALS, PANEL DISCUSSIONS BOTH LARGE AND SMALL, YOU WILL GET YOUR QUESTIONS ANSWERED AND CAN GET ALL THE LATEST INFORMATION ACROSS ALL FRONTS. THERE WILL ALSO BE LOTS OF SOCIAL AND NETWORKING OPPORTUNITIES INCLUDING MOM'S AND DAD'S NIGHTS OUT AND A DANCE PARTY FOR THE KIDS!

### **IS REGISTRATION CLOSED?**

REGISTRATION IS CLOSED. SOME EXCEPTIONS MIGHT BE MADE TO NEWLY DIAGNOSED FAMILIES.

### **WILL WE RECEIVE HELP BOOKING HOTEL ROOMS?**

LARRY FARRIS IS BOOKING HOTEL ROOMS FOR ALL ATTENDEES. **IF YOU HAVE CHANGES, NEW REQUESTS, OR QUESTIONS, PLEASE EMAIL** [LFARRIS@JORDANSGUARDIANANGELS.ORG](mailto:LFARRIS@JORDANSGUARDIANANGELS.ORG)

## **WHAT IS COVERED?**

THOSE PARTICIPATING IN THE ASSESSMENTS WILL RECEIVE ONE HOTEL ROOM PER FAMILY. YOU CAN ADD ADDITIONAL ROOMS AT YOUR COST FOR \$332 PER NIGHT. JGA COVERS FOOD ON JULY 12 AND 13. MEALS ON THE OTHER DAYS WILL BE UP TO YOU. WE ENCOURAGE FAMILIES TO COVER THE COST OF THEIR TRAVEL (AIR OR CAR) OR FUNDRAISE TO GET HERE; HOWEVER JGA HAS SCHOLARSHIPS AVAILABLE TO SUBSIDIZE TRAVEL IF NEEDED.

## **WHEN ARE ASSESSMENTS?**

JULY 8-11, YOU WILL HEAR DIRECTLY FROM BOSTON CHILDREN'S HOSPITAL ON WHEN YOUR DAY IS. PLEASE KEEP AN EYE ON EMAILS FROM JESSICA WAXLER!

## **WHAT DO THE ASSESSMENTS LOOK LIKE? WHAT WILL BE DONE?**

THE CONFERENCE IS BEING HELD IN BOSTON WHERE DR. CHUNG'S TEAM IS CURRENTLY LOCATED. IT'S THE EASIEST WAY FOR HER TEAM TO GATHER AS MUCH DATA AS POSSIBLE DURING THE CONFERENCE. THE TEAM AT BOSTON CHILDREN'S HOSPITAL (BCH) WILL ALSO BE ACCOMPANIED BY TEAM MEMBERS FROM COLUMBIA UNIVERSITY AND SEATTLE CHILDREN'S HOSPITAL. THE TEAM COMES TO THE HOTEL TO DO MOTOR ASSESSMENTS (FINE AND GROSS), NEUROLOGICAL TESTING, COGNITIVE TESTING, AND EEG'S. THIS NATURAL HISTORY STUDY DATA WILL BE USED AHEAD OF CLINICAL TRIALS TO FORM A BASELINE FOR THE POPULATION. ASSESSMENTS WILL BE DONE MON-THURS AND MANAGED BY BOSTON CHILDREN'S HOSPITAL. THEY WILL CONTACT YOU DIRECTLY AND WILL SCHEDULE YOUR APPOINTMENTS. YOU WILL SIGN 2 CONSENT FORMS FROM BCH. OUR GOAL IS TO COLLECT AS MUCH DATA AS POSSIBLE HOWEVER 100% OF PARTICIPANTS MAY NOT BE ABLE TO COMPLETE ALL ASSESSMENTS. ALL OF THE ASSESSMENTS ARE DESIGNED WITH CHILDREN AND ADULTS LIVING WITH JORDAN'S SYNDROME IN MIND AND ARE NOT MEANT TO BE STRESSFUL.

## **WHO IS SENDING OUT INFORMATION REGARDING ASSESSMENTS?**

-BOSTON CHILDREN'S HOSPITAL WILL BE CONTACTING YOU. PLEASE KEEP AN EYE OUT FOR EMAILS FROM JESSICA WAXLER, THE ASCEND STUDY AND BOSTON CHILDREN'S HOSPITAL. YOU WILL BE SIGNING 2 CONSENT FORMS ELECTRONICALLY BEFORE PARTICIPATING.

### **CAN I PARTICIPATE IF I DON'T SPEAK ENGLISH?**

Yes! We will have translation services available for everyone.

### **WILL SIMONS SEARCHLIGHT BE THERE?**

Yes! Simons will have stations set up (July 8 - July 11) so families can make sure they are caught up on all of their surveys and if blood samples have not been collected by Simons from the families, they can complete that as well. Please make sure you have signed up with Simons and have complete steps 1-4 on the dashboard. You will get an opportunity to catch up, register, or ask your questions during the conference. Simons Searchlight participation is preferred, but not required to attend the event.

### **WILL THE RESEARCH TEAM BE THERE?**

Yes, most if not all of the research team will be in attendance. They are bringing posters to outline the work they are doing and will be available to answer all of your burning questions about the incredible work they are doing.

### **WILL THERE BE CHILDCARE?**

Corporate Kids will once again be joining us for this conference. Children will be grouped by age and will be given age-appropriate activities to do and lots of time to play! Children are staffed according to need and one on one staffing is available. This is open to children with Jordan's Syndrome and their siblings (under 13) too. Children will be dropped off so you can attend meetings and then you will pick them up after each session for meals, free time etc. There will also be a non-supervised hang out room for the older kids (13 and older) in attendance who don't need supervision from Corporate Kids.

### **WILL THERE BE SIBSHOPS THIS YEAR?**

Yes! Our very own sibling Lexi Levine has been specially trained by SibShops to host special groups for our JGA siblings. The children will be grouped by age, 8-13 and 13+. These groups are designed to give an outlet to siblings of children with disabilities. It's a wonderful way to share and bond with other siblings.



TOGETHER WE STAND: JORDAN'S GUARDIAN ANGELS 2024 CONFERENCE  
JULY 12 - 13, 2024  
BOSTON MARRIOTT COPLEY PLACE

## **WHAT ARE WE DOING FOR MOM'S AND DAD'S NIGHTS OUT?**

PLANS ARE UNDERWAY FOR FUN NIGHTS OUT FOR PARENTS. MORE TO COME ON THIS!!  
SIMULTANEOUSLY, MOVIE NIGHTS ARE IN THE WORKS ON BOTH NIGHTS SO THERE WILL BE ENTERTAINMENT FOR THE KIDS AND THEIR PARENT STAYING BEHIND AS WELL. IF ONE PARENT IS ATTENDING AND YOU NEED HELP WITH THE KIDS, LET US KNOW!

## **IF I'M NOT ATTENDING, HOW DO I PARTICIPATE?**

AS FAR AS DATA COLLECTION GOES, IT'S IMPERATIVE THAT YOU GO ONLINE AND FILL OUT YOUR INFORMATION WITH SIMONS SEARCHLIGHT. MAKE SURE YOU ARE UP TO DATE! CONFERENCE SESSIONS WILL ALSO BE RECORDED AND WILL BE POSTED ONLINE AT A LATER DATE FOR FAMILIES TO VIEW.

## **WILL THERE BE ON-CAMERA INTERVIEWS THIS TIME?**

YES! JGA WILL BE CONDUCTING ON-CAMERA INTERVIEWS FOR FAMILIES TO TELL THEIR STORIES ON THURSDAY JULY 11 ALL DAY! SIGN-UP SHEETS WILL BE OUT SOON, BUT THIS IS THE PERFECT OPPORTUNITY TO CHAT AND TAKE PART IN VIDEOS PRODUCED BY JGA. ALL OF THE MATERIAL IS USED IN-HOUSE AND WE POST THE VIDEOS TO SHOW THE WORLD WHAT WE ARE DOING.

**OUR GOAL IS TO MAKE THIS WEEK EASY, INFORMATIVE AND FUN! WE CAN'T WAIT TO SEE YOU ALL!**

