

# The Dystroglycanopathies: 2019 Patient and Family Conference

Saturday, June 22, 2019 at the  
Coralville Marriott Hotel & Convention Center  
300 E 9<sup>th</sup> Street  
Coralville, Iowa 52241

The patient and family conference is free and open to anyone interested in the dystroglycanopathies. People with a dystroglycanopathy diagnosis are welcome to participate in natural history research.

## Lodging

- To make a room reservation at the **Marriott Coralville Hotel** call 1-319-688-4000.
- Hotel information and room reservations available at [Book your group rate for UI Wellstone Muscular Dystrophy Conference](#).
- Hotel reservations must be received by **May 31, 2019** to obtain discounted rate (\$115/night).

## Conference Registration

- All conference attendees must be registered by **May 31, 2019**.
- <https://centerforconferences.uiowa.edu/dystroglycanopathies-2019-patient-and-family-conference>

## Participation in Research

- If you are interested in participating in the *Clinical Trial Readiness for the Dystroglycanopathies* natural history study and you are a new participant please contact Carrie Stephan at [carrie-stephan@uiowa.edu](mailto:carrie-stephan@uiowa.edu) or 319-356-2673.
- Research Exams are scheduled on a first-come, first-served basis.
- The number of study exams that can be performed Friday morning and Sunday morning is limited. If your travel arrangements allow, we appreciate your flexibility as we schedule appointments. Please specify any travel constraints on the Registration Form.
- You will receive an email notification of your study visit date and time.
- Please bring your most recent medical records including test results obtained locally to your study exam.
- Wear comfortable clothing and footwear appropriate for walking.
- Please allow 4-5 hours for your exam. New participants may take longer.

## Directions to the Clinical Research Unit for Study Exams

- Exams take place on the **Clinical Research Unit (CRU)** at the **University of Iowa Hospitals & Clinics**, 200 Hawkins Drive, Iowa City, Iowa 52242. Map: <https://uihc.org/parking-and-map>.
- Parking in Hospital Ramp #1 is closest to the CRU.
- **Inside the hospital**, take **Elevator A** (far north end of the hospital) to **2<sup>nd</sup> floor**. Turn right (north) as you exit the elevator. At the 'T' in the hall, turn left (west) and proceed to the end of the hall.

## **Muscular Dystrophy Research Lab Tours**

Friday June 21, 2019 from 2:00-5:00 pm

- **This is your opportunity to see muscular dystrophy research up close!**
- **Join Dr. Kevin Campbell, Dr. Steve Moore and many dedicated researchers** for tours and presentations.
- The **Iowa Muscular Dystrophy Research Center Laboratories** at the University of Iowa Carver Biomedical Research Building. Address: 4283 Carver Biomedical Research Building. Parking is available in the Newton Road Ramp, 426 Newton Road, Iowa City, IA 52242.

## **Welcome Reception**

Friday evening 6:00-8:00 pm at the Coralville Marriott Hotel

- **Relax after your travels!** Meet old friends and make new friends in the Marriott Hotel. Refer to electronic screens throughout the hotel for meeting locations.
- Snacks will be served. Cash bar available.

## **Conference Sessions**

Saturday 9:00 am to 5:00 pm at the Coralville Marriott Hotel

- **Presentations and Q&A** about the dystroglycanopathies, research, and self-care in large and small group settings.
- Held in the Marriott Coralville Hotel & Convention Center. Refer to electronic screens throughout the hotel for meeting locations.
- Conference rooms are often cool, so please bring a sweater or light jacket.
- **Family Activity Area** is available during morning and afternoon conference sessions.

## **Travel**

**\*\*You must arrange your own travel to study exams and lab tours\*\***

- The **Eastern Iowa Airport in Cedar Rapids (CID)** <https://flycid.com> is approximately 20 minutes from Iowa City. Other commercial airports in/around Iowa include **the Quad City International Airport (MLI)** in Moline, Illinois <https://www.qcairport.com/>, which is approximately one hour from Iowa City, and the **Des Moines International Airport (DSM)** <http://www.dsmairport.com/>, which is ~ two hours from Iowa City. Airfare may vary quite a bit between these airports.
- **Rental cars** are available at the airports.
- **Shuttle service** is available from the Eastern Iowa Airport through Airport Shuttle Service (800) 725-8460 and Express Limousine Service (319) 626-5466. Both shuttle services are available for all flights, but reservations must be made in advance.
- **Taxi Service:** Uber and Lyft are available.

## **Accessible Transportation**

- **Rental of wheelchair vans** may be available through Siebert Mobility (877) 543-8826 ([www.siebertmobility.com](http://www.siebertmobility.com)).
- **Wheelchair accessible shuttle service:**
  - 1) Non Emergent Transport 563-299-3513 [www.netmuscatine.com](http://www.netmuscatine.com)
  - 2) To The Rescue Transportation Services 319-826-6068 [www.totherescue.net](http://www.totherescue.net)
  - 3) American Class Taxi (319) 363-8294 <http://americanclasstaxi.com/>

**\*Call at least two days ahead for wheelchair shuttle services\***

## **Conference Weekend Schedule of Events**

### **Thursday, June 20**

Research Exams 9:00 am-5:00 pm

### **Friday, June 21**

Research Exams 8:00 am- 5:00 pm

Iowa Muscular Dystrophy Research Center Lab Tours 2:00-5:00 pm

Welcome Reception 6:00-8:00 pm

### **Saturday, June 22**

Continental Breakfast 8:00-9:00 am

Conference 9:00 am-5:00 pm

Social Gathering 5:00-6:00 pm

Dinner on your own

### **Sunday, June 23**

Research Exams 8:00 am-5:00 pm

## **Conference Program**

Welcome

Dystroglycanopathy Natural History Study Updates

Glycosylation

Breakout Session 1\*

Navigating Clinical Trials

Breakout Session 2\*

Participant Panel

Conference Conclusion

### **Breakout Sessions\***

Medical Q&A - Science Q&A

Photo Booth - Adaptive Yoga

Teen Breakout - Caring for Someone with MD

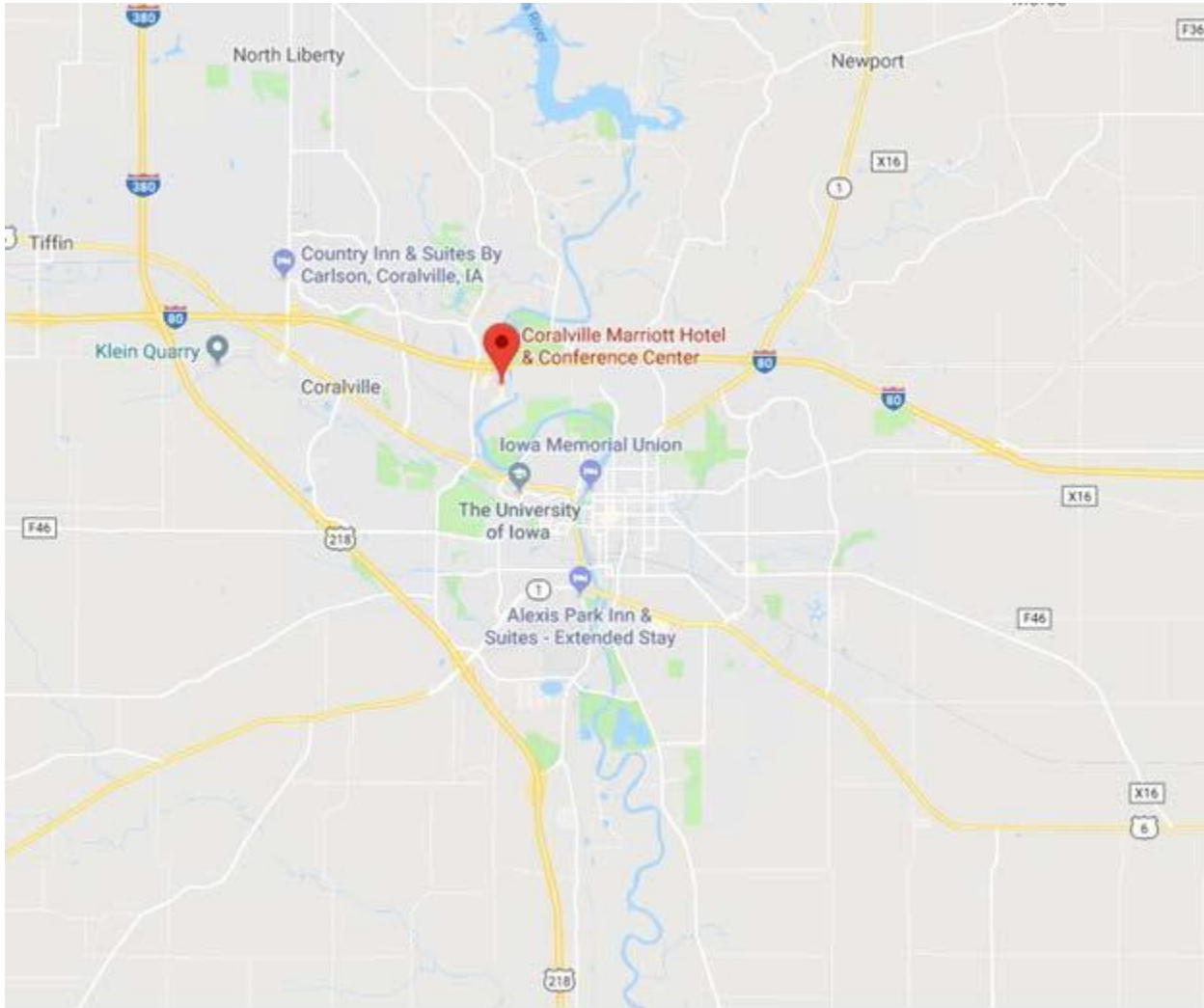
**Teen/Tween/Young adult social area will be available during the Friday evening reception, Saturday morning breakfast and the early morning science presentations.**

**Family Activity Area is available during morning and afternoon conference sessions for young children. The Activity area is supervised by volunteers who are not trained to provide medical care.**

**If you have any questions about the conference or research exams, please contact Carrie Stephan at [carrie-stephan@uiowa.edu](mailto:carrie-stephan@uiowa.edu) or (319) 356-2673.**

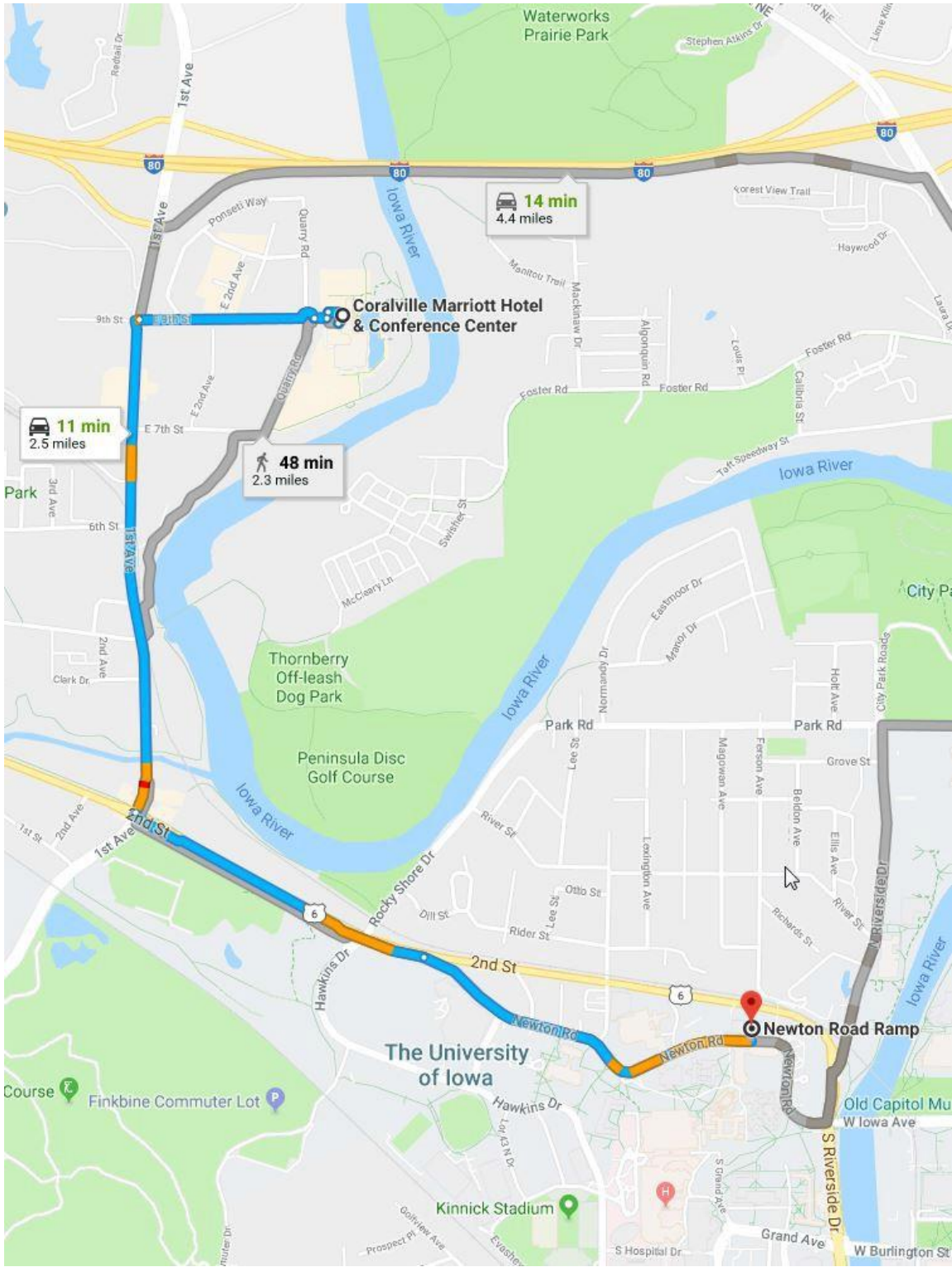
## **Driving to the Marriott Coralville Hotel & Convention Center**

- The Marriott is located at Exit 240 off Interstate 80 in Coralville, just north of The University of Iowa campus and hospital.
- **For GPS, the Marriott address is 300 E 9<sup>th</sup> Street, Coralville, IA 52241**



## **Lab Tours: Driving to Carver Biomedical Research Building (CBRB)**

- **NOTE: Do not put CBRB into your GPS, instead put the address of the Newton Road Ramp at 426 Newton Road, Iowa City, IA 52246**
- From the Marriott, proceed West on E 9<sup>th</sup> Street towards 1<sup>st</sup> Avenue
- Stay on 1<sup>st</sup> Avenue until you hit 2<sup>nd</sup> Street
- Use the two left lanes to turn left onto 2<sup>nd</sup> Street
- Continue beyond stop light at Hawkins Drive
- Take a slight right fork onto Newton Road
- Newton Road Parking Ramp will be on your left, park here
- The Biomedical Research Building is across the street from the ramp



## Study Exams: Directions to University of Iowa Hospitals (Boyd Tower)

- For GPS, the hospital address is **200 Hawkins Drive, Iowa City, IA 52242**
- Proceed West on E 9<sup>th</sup> Street towards 1<sup>st</sup> Avenue
- Stay on 1<sup>st</sup> Avenue until you hit 2<sup>nd</sup> Street
- Use the two left lanes to turn left onto 2<sup>nd</sup> Street
- Turn right onto Hawkins Drive
- After passing Hospital Parking 3, turn left onto Hospital Loop Drive
- Follow the Loop until you arrive at Hospital Parking 1- this is nearest to Boyd Tower
- Hospital map is located here: <https://www.uihealthcare.org/yourvisit.aspx?id=15367>
- Once inside the hospital, proceed to Elevator A at the far north end of the hospital.
- Take elevator A to 2<sup>nd</sup> floor. Turn right immediately when exiting the elevator.
- The short hallway ends in a 'T', go left to the end of the hall. The CRU is on the right. Check in at the desk.

