

# The Dystroglycanopathies: 2018 Patient and Family Conference

Saturday, July 14, 2018 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 is available at <https://www.marriott.com/hotels/travel/cidic-coralville-marriott-hotel-and-conference-center/>
- A block of rooms has been reserved under 'Wellstone Muscular Dystrophy Conference' with a room rate of \$113 plus tax.
- **Hotel reservations must be received by Friday June 29, 2018 to obtain discounted rate.**

## Conference Registration

- **All conference attendees must be registered.**
- Link to register for the conference, <https://centerforconferences.uiowa.edu/2018-dystroglycanopathies-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: <http://www.uihealthcare.org/parking-and-wayfinding/>.
- 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

- A chance to see muscular dystrophy research up close!
- The **Iowa Muscular Dystrophy Research Center Laboratories** at the University of Iowa Carver Biomedical Research Building will be open on Friday, July 13, 2018 from 2:00-5:00 pm.
- **Join Dr. Kevin Campbell, Dr. Steve Moore and many dedicated researchers** for tours and presentations. Address: 4283 Carver Biomedical Research Building, 285 Newton Road, Iowa City, IA 52242. Map: <http://maps.uiowa.edu/crb>. Parking is available in the Newton Road Ramp.

## Welcome Reception

- **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

- **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

- The **Eastern Iowa Airport in Cedar Rapids (CID)** <http://www.eiairport.org/> is approximately 20 minutes from Iowa City. Other commercial airports in/around Iowa include the Quad City International Airport in Moline, Illinois (MLI) <http://www.qcairport.com/>, which is about one hour from Iowa City, and the Des Moines International Airport (DSM) <http://www.dsmairport.com/>, which is about 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 Emergency 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) Care Ambulance (319) 512-8811 <http://www.careambulance.us/services.htm>
  - 4) American Class Taxi (319) 363-8294 <http://americanclasstaxi.com/>
  - 5) Southeast Iowa Ambulance Service 319-466-0735 [www.seiowaambulance.com](http://www.seiowaambulance.com)
- **Call at least two days ahead for wheelchair shuttle services.**

**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.**

# Conference Weekend Schedule of Events

## **Thursday, July 12**

Research Exams 9:00 am-5:00 pm

## **Friday, July 13**

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, July 14**

Continental Breakfast 8:30 am

Conference 9:00 am-5:15 pm

Social Gathering 5:30-6:00 pm

Dinner and Entertainment 6:00-8:00 pm

## **Sunday, July 15**

Research Exams 8:00-5:00 pm

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## Conference Program

Welcome

Scientific Advances

Dystroglycanopathy Natural History Study Updates

Breakout 1\*

A Roadmap for Bringing Gene Therapies into Clinical Use

Breakout 2 \*\*

Nutrition in the Dystroglycanopathies

Participant Panels

### Breakout 1 Sessions\*

Public Policy-Current Issues and Next Steps

Science Q&A

Until A Cure: Dealing with Difficult

Feelings that Come with MD

### Breakout 2 Sessions\*\*

CMD Group Discussion

Medical Q&A

Yoga and Sound Healing

Family Activity Area is available during morning and afternoon conference sessions.

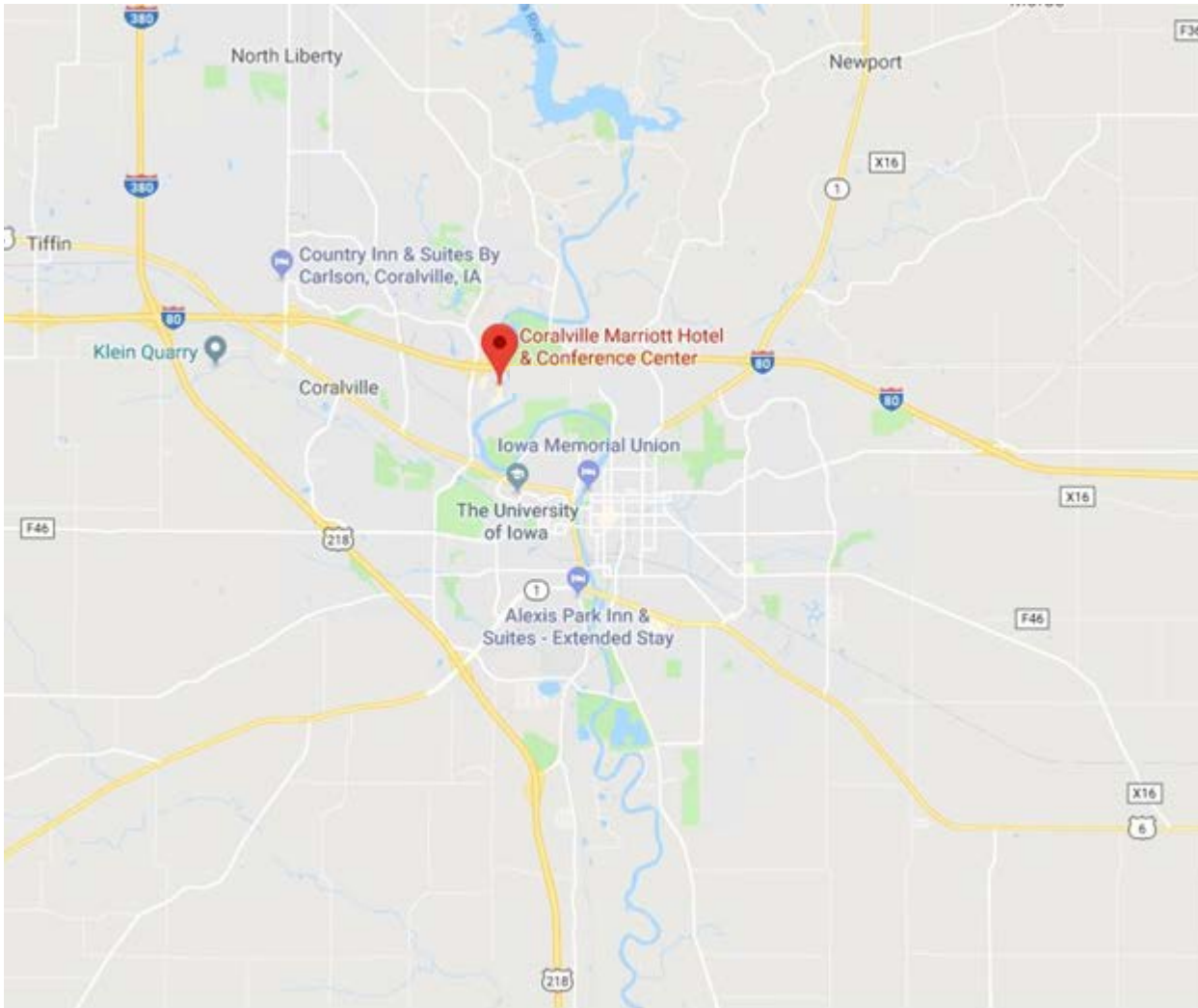
Please note that the Activity area is supervised by

Child Life and Therapeutic Recreation

volunteers who are not trained to provide medical care.

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

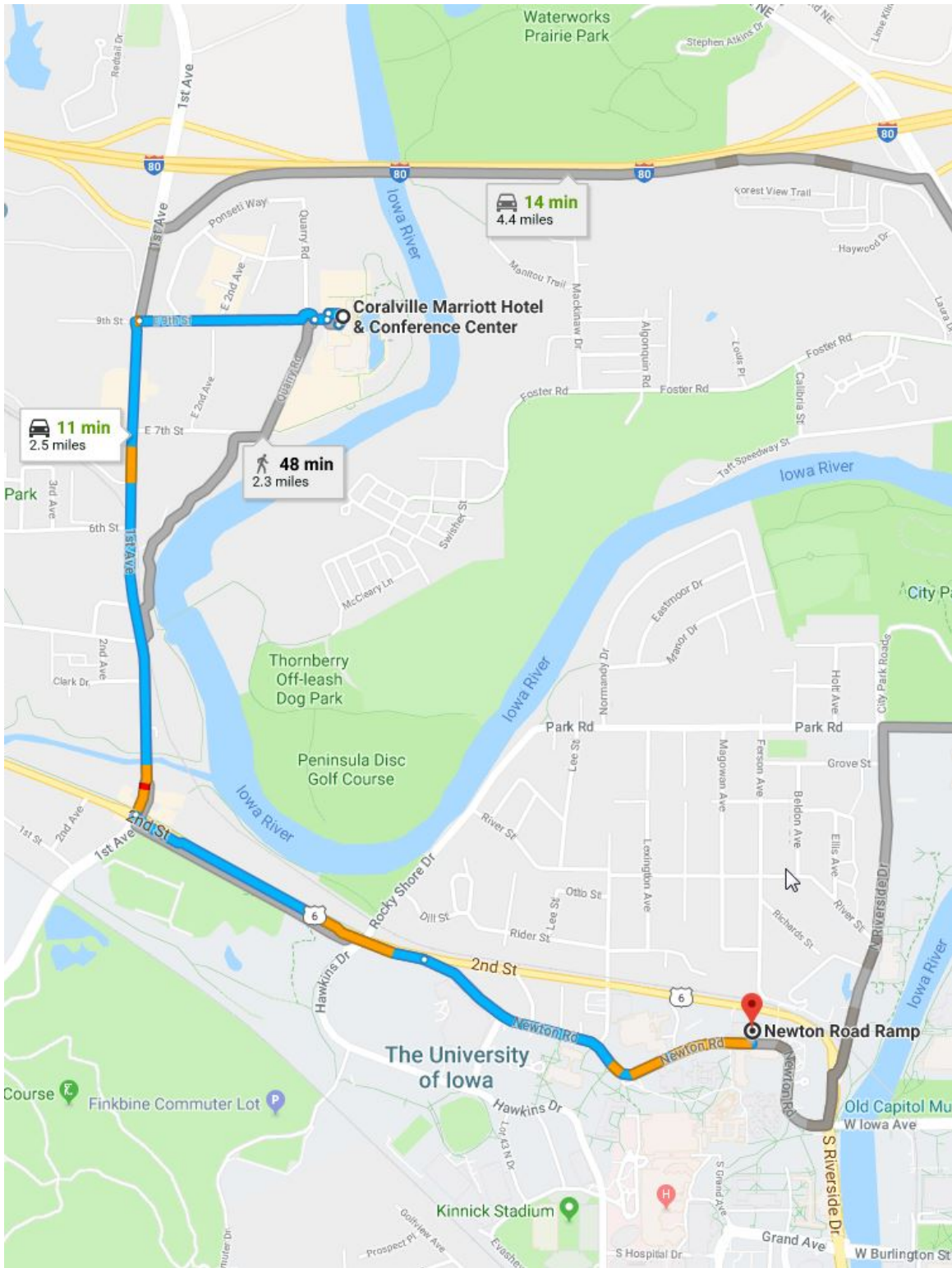
- The Marriot is located at Exit 240 off Interstate 80 in Coralville, just north of The University of Iowa campus and hospital.
- **For GPS, the Marriot address is 300 E 9<sup>th</sup> Street, Coralville, IA 52241**



## **Lab Tours: Driving to Carver Biomedical Research Building**

- 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
- **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**





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

- 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.
- **For GPS, the hospital address is 200 Hawkins Drive, Iowa City, IA 52242**

