



July 7<sup>th</sup>, 2019

Dear Conference Attender,

On behalf of the Speak Foundation, we thank you for registering for our National Limb Girdle Muscular Dystrophy Conference! Our National LGMD Conference is the first event ever uniting all forms of LGMD to find new and emerging treatments. Our leadership team of Dr. Brad Williams, Carol Abraham, and myself are all looking forward to having you attend this historical event over Labor Day at the Hyatt Regency Chicago, 151 East Wacker Drive, Chicago, IL 60601.

The hotel is the largest in the city and located near the Navy Pier, Museum of Science and Industry, Michigan Avenue, Millennium Park, and the world-famous stores and restaurants on Magnificent Mile. If you have already booked your room and have follow up questions, please make sure to contact the hotel if you have special requests concerning your room via [alex.hussain@hyatt.com](mailto:alex.hussain@hyatt.com). Please note the conference is unable to modify any existing reservation as these are done through your reservation. In addition, if you haven't booked your room for the event, our room reservation link for our hotel is at <https://book.passkey.com/event/49802869/owner/2135/home>

To help you better plan your schedule, we have also included our conference schedule in a PDF attached. This schedule includes our line-up of speakers and times each day we are meeting. We hope that will be of assistance to you as you make your travel plans. We have also included an accessible travel guide to Chicago that the city graciously prepared for us! Please also note that the best travel from the airport is through a company called OPEN DOOR taxi which provides accessible wheelchair transport <http://www.opentaxis.com/>

We are also pleased to inform you about two clinical studies on LGMD that will be occurring at the Conference.

- A genetic study conducted by Dr. Peter Kang, MD, of the University of Florida. This study will involve collection of DNA samples. The objective of this study is to discover additional genes and genetic changes which can cause LGMD.
- An observational study of two prospective outcome measures being evaluated for LGMDs, conducted by Dr. Linda Lowes, PhD, of Nationwide Children's Hospital

Gait mapping—a computer analysis of the patients' gait (for ambulatory patients)

Workspace volume—analysis of the flexibility of patients' upper body (for both ambulatory and nonambulatory patients).



The National LGMD Conference is a program and project of the Speak Foundation.

These outcome measures, if they provide a good assessment of an LGMD patient's function, may be used in future clinical trials.

More information about these studies is given. If you are interested in participating in either of these studies, please contact the study coordinators directly in advance of the Conference with questions. Enrollment in these studies, and determination of a patient's eligibility to participate, can only be done by the study coordinators.

The Speak Foundation does not make any recommendation regarding participation in these studies—patients interested in participating should carefully consider the information given in the Informed Consent for in making a decision on whether to participate.

Nothing great has ever happened without someone first believing it was possible. We look forward to seeing you in Chicago August 30th to September 2nd, 2019!

**Together we are Stronger,**

Kathryn Bryant

President and CEO, Speak Foundation

National LGMD Conference Administrator



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