

CdLS National Family Conference 2018: FAQ Sheet

When is conference?

June 28th – July 1, 2018

Where is conference being held?

Marriott City Center, 30 South 7th Street, Minneapolis, MN 55402

How much is registration?

Adult registration is \$350 before March 29 and \$390 after. Children under 18 are \$180 and \$205, respectively. Non-parent/guardian providing childcare, \$230 and \$260, respectively. There is no charge for children two and under or anyone with CdLS.

What does the registration fee cover?

Registration covers workshops, general sessions, consultations, the Saturday banquet and all meals from Thursday night ice cream social through Sunday breakfast. If you arrive before Thursday or stay after Sunday, there is a restaurant onsite and others nearby.

Are scholarships available?

Scholarships for families living within the U.S. are available for first-time attendees only. Scholarships are given out on a first-come, first-served basis.

All registration forms seeking scholarship funding are due March 29, 2018.

What does a scholarship for first-time attendees cover? And how do I apply?

Scholarship will cover up to two registration fees only, in addition to the individual with CdLS (who is never charged). Additional family members will be charged. The scholarship does not cover fees for either of the sibling programs (Tiny Tots or Kids Explore!), your hotel room or any travel or personal expenses at conference.

Those seeking any type of conference scholarships will have the opportunity to select that option through the online registration. Applicants will be notified within two weeks of submitting their online registration/application if they have been awarded scholarship.

What about the grandparent scholarship?

We are offering scholarships for two grandparents this year (either one pair, or two single scholarships). Like the family scholarship, it covers registration fees only. Grandparent scholarships are available for first-time conference attendees only.

Those seeking any type of conference scholarships will have the opportunity to select that option through the online registration. Grandparent awardees are chosen randomly and will be notified during the first week in April.

How do I get from the airport to the hotel?

The hotel does not have a shuttle from the airport. The hotel is about 20 minutes from the Minneapolis, Saint Paul airport. You can also take a taxi/cab/Uber/Lyft.

Do I need to make my hotel reservation?

The CdLS Foundation conference rate is \$129/night plus tax. **This rate is only for people who are registered for conference.** Once you register for conference, you will be directed to the hotel website to make your overnight accommodations. The discounted room block rate is available until May 23, or until it sells out, whichever comes first.

Please note: a special registration type has been created for people *who do not want to attend conference*, but do want to attend the banquet and hangout with all of their friends. However, our room block (discounted rate) is reserved *only for those who are actually attending the conference.*

Does the hotel have in-room refrigerators for medicine/formula?

Refrigerators are available, but it is recommended that families verify this request with the hotel upon reserving your room.

Are cribs available?

Yes, however you must request a crib through the hotel when you reserve your room.

When should I arrive for conference?

Thursday, June 28 at 2 p.m. Registration begins on Thursday at 2 p.m. There is a mandatory childcare meeting at 7 p.m. for all families planning to utilize any of the childcare programs while at conference. We will have an ice cream social at 7:30 p.m. The registration/information desk is open into the evening.

What options are there for food allergies, vegetarian options and people with CdLS?

All meals include “CdLS-friendly” items such as mashed potatoes, applesauce, jell-o, and soup. The hotel cannot provide a blender in the dining room.

Vegetarian options are available at all meals.

If you or a member of your family has a food allergy, please notify the food service manager at the hotel. It is recommended that you follow up with the food service manager representative at each meal.

What are my childcare options?

Children with CdLS (any age) can attend **Jindi's Place** at no cost. The program has specially trained volunteers and has been overseen by the same family for more than 20 years. Activities include arts and crafts, movies, games, toys, reading, music and a quiet room. Arrangements can be made for tube and bottle feedings. The program closes for an hour and a half during lunch each day, and parents/caregivers are responsible for picking up their child(ren) during this time.

Programs for siblings on Friday and Saturday are as follows:

- § **Tiny Tots** is for siblings aged six months to seven years. The Foundation contracts with an outside childcare provider to be on site. The program closes for an hour and a half during lunch each day, and parents are responsible for picking up their child during this time.
- § **Kids Explore!** is for siblings ages five to 17. Participants go off-site for both days. Lunch is provided. This year, *Kids Explore!* will go to the *Science Museum of Minnesota* and *The Como Park Zoo and Conservatory*. If an adult is interested in chaperoning their child on *Kids Explore!*, the same fees apply.

Individuals with CdLS over the age of five can participate in *Kids Explore!* if they have a paying chaperone over the age of 18 to accompany him/her. If the child doesn't have a chaperone available, the Foundation will attempt to find a volunteer, but cannot be guaranteed.

The cost is \$140 per child for two days and \$85 for one day. There is a 10% discount for each additional child per family.

There is a **mandatory meeting Thursday at 7 p.m.** for those using any of the childcare programs.

What should I wear at conference?

Although conference is taking place during the summer, sessions and activities are held in air-conditioned rooms, so layers are recommended. *Kids Explore!* participants should dress for summer weather and wear comfortable walking shoes.

How do the consults work?

When you register for conference, be sure to fill out the consultation request form, where you can select your top three consultation choices. We will do our best to accommodate all requests. Once at conference, you will be given the times/days of your consults and information on where to go. All new families will first meet with a geneticist.

Consults take place Friday and Saturday in a designated area of the hotel. In some consultations, there may be more than one professional in the room assisting. Consults run from 15 to 30 minutes. While we do our best to keep things on schedule, we appreciate your patience if there are any delays.

During a consultation, you may also be asked for a sample of your child's blood or to participate in a research study. You are under no obligation to participate.

Is any research associated with the professionals attending conference?

As with every conference, there are opportunities to participate in research projects that benefit people living with CdLS. Your participation is never required. Families are encouraged to make decisions that are best for themselves and their child.

What if I miss a workshop?

Oftentimes, presenters will have handouts that can be requested or you can request a copy of the PowerPoint presentation after conference.

What happens at the Saturday night dinner?

Saturday is an evening of food, music and dancing. It's also an opportunity to recognize people who have made a difference in the lives of people with CdLS.

The banquet is included for all registered attendees. Banquet fees for non-conference attending guests are \$55 for adults and \$35 for children under age 18. Tickets may be purchased through registration, or by calling the Foundation.

Are there photographers?

The Foundation will have a professional photographer (or two) at conference to capture the memories. Photographs taken at general sessions, meals, activities, and receptions may be used in future Foundation publications.

What's the mentoring program I've been hearing about?

First-time families are matched with a veteran conference-goer and connect via telephone, video conference or email at least once prior to conference. The mentor provides information about the conference experience and answers questions regarding the event. Families are encouraged to meet face-to-face during a "Meet Your Mentor" session Thursday afternoon, or during free time Friday.

How do I participate in the mentoring program?

You will have the opportunity to select that through the online registration.

Any other tips for first time attendees?

Take a deep breath, relax and enjoy. It may seem a bit overwhelming at first—especially if you have never seen another child with CdLS before—but you'll quickly find conference is one big family gathering. In between workshops and informational sessions, there's plenty of time for making new friends and sharing stories.

