



NATIONAL FAMILY CONFERENCE

REGISTRATION PACKET



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

302 West Main Street, #100 • Avon, CT 06001-3681
860.676.8166 • toll free: 800.753.2357 • fax: 860.676.8337 • www.CdLSusa.org

CdLS FOUNDATION NATIONAL FAMILY CONFERENCE

Join us for the Cornelia de Lange Syndrome (CdLS) Foundation National Family Conference, June 21-24, 2012. This year's conference theme is inspired by the Illinois state insect: the Monarch butterfly. The event aims to help individuals with CdLS *grow, transform* and *soar* to reach his/her potential.



Attendees have an opportunity to gain a wealth of knowledge on how to best care for their child with CdLS and meet other families facing similar challenges. Individuals with CdLS receive free head-to-toe consultations with experts from a range of medical and educational fields.

Not only will attendees be better equipped to face challenges throughout their children's lives, but they will also leave with a sense of belonging. There are many events throughout the conference that help connect families. There is a gathering for grandparents, separate get-togethers for moms and dads, an ice cream social, and a Saturday night banquet with food, dancing and fun for everyone.

Pre-conference fun

Come a day early and join us for a golf tournament, taking place at Crane's Landing, the resort's 18-hole golf course, on Wednesday, June 20. Call 800.753.2357 or email events@CdLSusa.org for more details or to participate.



QUESTIONS?

Call the Foundation office at 800.753.2357 or email familysupport@CdLSusa.org.

HOTEL INFORMATION

The conference takes place in Lincolnshire, IL, at the Lincolnshire Marriott Resort, located 45 minutes from Chicago's O'Hare International Airport and one hour from Midway Airport. Amenities include indoor and outdoor pools, exercise room, jogging trails, golf course, several on-site restaurants, and a Starbucks kiosk.

Guest Room Rates:

Provide the group code **CDLCDLA** to get the CdLS Foundation Conference rate and benefits.

Single and Double Occupancy: \$109.00 + tax.



To make hotel reservations:

Phone: 847.634.0100
Toll-free: 888.236.2427
Group Code: **CDLCDLA**

Reservation Deadline:

The hotel reservation deadline is **May 25.**

GENERAL INFORMATION

REGISTRATION

You must be pre-registered to attend the conference. The early bird registration deadline is **March 26**. The final deadline for registering is **May 17, 2012**.

The registration fee covers attendance at all workshops and general sessions, medical and educational consultations, and all meals from Thursday dinner through Sunday breakfast, including the Saturday banquet. (Tickets are available to purchase for non-registered guests to attend the Saturday banquet. See the registration form to purchase.) There is no registration charge for children or adults with CdLS.

Registration **does not** include the hotel reservation. Contact the hotel directly to make these arrangements. The *Kids Explore!* program for siblings is also extra.

CHILDCARE PROVIDER REGISTRATION: Available to individuals attending conference **solely** to provide childcare. If you take advantage of this discount option, childcare for the person with CdLS is not available.

ONE-DAY PROFESSIONAL REGISTRATION: This allows professionals from such fields as medicine, education and more an opportunity to attend Friday or Saturday general sessions and workshops. (This is not the same as the Scientific or Educational Symposia on Thursday. Professionals who wish to attend the symposia must contact the Foundation directly for a separate registration form.)

SPECIAL GUESTS/PRESENTERS/CONSULTATION PROVIDERS: Those attendees designated as special guests, or who are presenting at a workshop and/or providing consultation to families, do not have to pay the registration fee. However, they are required to fill out the registration and sign the release form.

Cancellation Policy: Any cancellations after **June 1, 2012**, are subject to a **\$50 charge per person**.

FIRST TIME ATTENDEES SCHOLARSHIPS

Scholarships are offered to families attending their first conference. Each scholarship is limited to the cost of registration for a maximum of two adults and two children. The scholarship does not cover travel, hotel or the *Kids Explore!* program. To apply for a scholarship, select the option under Special Requests on the registration form. Scholarships are awarded on a first-come, first-served basis. You will receive notice of the status of your request within two weeks. *Pre-payment of registration fees is not necessary if you apply for a scholarship.*

Deadline is March 26.

GRANDPARENT SCHOLARSHIPS

Two scholarships are available to cover the registration costs for up to two grandparents within the same family to attend. A drawing is held April 13. **Deadline is March 26.**

FUNDRAISING ASSISTANCE

Many community organizations are responsive to the needs of families wanting to attend conference. We urge families to seek financial support through your state ARC, local school systems, social service agencies, national/state disability programs, regional businesses, and/or service clubs, emphasizing the opportunity for the person with CdLS to be seen by a team of CdLS experts.

REGISTRATION	EARLY-BIRD	AFTER 3/26
Adult	\$320	\$350
Person providing childcare	\$220	\$235
Children under age 18	\$170	\$195
Person with CdLS	No charge	No charge
One-day professional	\$250	\$250
Childcare options		
<i>Kid Explore!</i> (ages 5– 17)	\$95	\$110
Tiny Tots and childcare for people with CdLS (all ages)	No charge	No charge

CONFERENCE AGENDA

	THURSDAY	FRIDAY	SATURDAY	SUNDAY
7am		7-8 ³⁰ Breakfast	7-8 ³⁰ Breakfast	7-9 ³⁰ Farewell Breakfast
8am				
9am		9-10 ³⁰ Medical and Research Updates	9 ¹⁵ -10 ¹⁵ Communication 9 ¹⁵ -12 ¹⁵ Protected Tomorrows	
10am				
11am		10 ⁴⁵ -11 ³⁰ Genetics, Behavior & Gastrointestinal Issues *	10 ³⁰ -11 ¹⁵ Nutrition	
noon		11 ³⁵ -12 ²⁰ Genetics, Behavior & Gastrointestinal Issues*	11 ¹⁵ -12 ¹⁵ ABC's of Feeding & Communicating without Words*	
1pm		12 ³⁰ -1 ³⁰ Lunch	12 ³⁰ -1 ³⁰ Lunch	
2pm	Registration Opens	1 ⁴⁵ -2 ⁵⁰ Grow with Me. The Success of Adults with CdLS	1 ⁴⁵ -2 ⁴⁵ Candee Fick: Making Lemonade	
3pm		3-3 ⁴⁵ Successful Fundraising, Mildly Affected Youth, Grandparents Perspective & Strategic Planning*		
4pm	4-4 ⁴⁵ First-Time Families Orientation	4-4 ⁴⁵ Successful Fundraising, Planned Giving & Strategic Planning*		
5pm	5-7 Pasta Dinner	4 ⁴⁵ -6 Meet the Experts 5-7 Dinner		
6pm				
7pm	7-8 Childcare Orientation	6 ⁴⁵ -8 Moms Meeting 7-9 Ice Cream Social	6 ³⁰ -10 Banquet	
8pm		8 ¹⁵ -9 ³⁰ Dads Meeting		
9pm				
10pm				

KEY

- Workshop/Meeting
- General Session
- Food

Schedule is subject to change

* = multiple workshops at once

REGISTRATION FORM

MAIL OR FAX COMPLETED FORM WITH PAYMENT

GENERAL INFORMATION (Please print clearly)

Full name (or last name of family if registering a family) _____ First-time attendee(s)

Person with CdLS _____ Date of Birth (D.O.B) _____

Address _____

City _____ State _____ Zip Code _____ Email _____

Day Phone _____ Evening Phone _____ Cell Phone _____

Would you like to be included in our Conference Directory of attendees? Yes No

For families or multiple attendees, list all first/last names as they should appear on name tags.

Name: _____ D.O.B _____ Relationship to Person with CdLS: _____

Name: _____ D.O.B _____ Relationship to Person with CdLS: _____

Name: _____ D.O.B _____ Relationship to Person with CdLS: _____

Name: _____ D.O.B _____ Relationship to Person with CdLS: _____

Name: _____ D.O.B _____ Relationship to Person with CdLS: _____

TRAVEL RELATED INFORMATION (You must reserve a room directly with the hotel)

Will you be staying at the Marriott? Yes No # Nights Reserved _____ #Rooms Reserved _____

Please indicate when you expect to arrive at the hotel: Date: ____/____/____ Time: _____ am/pm

Please indicate when you are planning to leave the hotel: Date: ____/____/____ Time: _____ am/pm

SPECIAL REQUESTS

First-Time Attendees Scholarships: Grandparent Scholarship: \$ _____ amount requesting (deadline March 26)

How many of the following will you need? Booster seats _____ High chairs _____

Please Indicate: food allergies vegetarian/vegan

CONFERENCE REGISTRATION FEES

Conference registration fees cover all meals from Thursday dinner through Sunday breakfast, all conference workshops and sessions, and professional consultations.

REGISTRATION	EARLY BIRD	REGULAR (after 3/26)	# OF ATTENDEES	TOTAL
Adult(s)	\$ 320	\$ 350	_____	\$ _____
Person providing childcare	\$ 220	\$ 235	_____	\$ _____
Children under 18	\$ 170	\$ 195	_____	\$ _____
One Day Professional	\$ 250	\$ 250	_____	\$ _____
Person(s) with CdLS	no charge	no charge	_____	\$ <u>0</u>
Presenter/Consult Provider	no charge	no charge	_____	\$ <u>0</u>
Special Guest	no charge	no charge	_____	\$ <u>0</u>

ADDITIONAL SERVICES

<i>Kids Explore!</i>	\$ 95	\$ 110	_____	\$ _____
<i>Kids Explore!</i> (chaperone)	\$ 95	\$ 110	_____	\$ _____
Guests for Saturday Banquet (non-registered)		\$ 40	_____	\$ _____
Guests under age 18 for Saturday Banquet (non-registered)	\$ 25		_____	\$ _____

Grand Total: \$ _____

PAYMENT METHOD

Check enclosed (payable to the CdLS Foundation). Please charge my Master Card Visa American Express

Account Number _____ Expiration Date ____ / ____

Signature _____ Security Code _____

RELEASE FORM

RETURN WITH REGISTRATION

LIABILITY, INFORMATION AND PHOTO RELEASE

All adults attending the 2012 CdLS Foundation National Family Conference must complete this form.

- I release the CdLS Foundation, its employees, board members and officers, and volunteers from any liability whatsoever arising from any conduct including any alleged negligence by act or omission of the CdLS Foundation in connection with my attendance at the 2012 conference.
- I give permission to the CdLS Foundation to release my name to professionals participating in the 2012 conference.
- I give permission to the CdLS Foundation to use my name and image (photographs and/or video) as well as that of family members at the 2012 conference to be published in CdLS Foundation publications.
- I give permission to the CdLS Foundation to use my name and image (photographs and/or video) as well as that of family members at the 2012 conference to be used for publicity purposes.

The dated signature of each attending adult is **required** below:

Printed Name _____ Signed _____ Date _____

Printed Name _____ Signed _____ Date _____

Printed Name _____ Signed _____ Date _____

Printed Name _____ Signed _____ Date _____

AUTHORIZATION TO CONSENT TO TREATMENT OF A MINOR

If a child is attending the 2012 CdLS Foundation Family National Conference, the child's Legal Guardian must sign a consent to the following:

In case of sudden illness or accident, and in case I cannot be reached, I, the undersigned legal guardian of a minor, have authorized (by virtue of my signature below) the Cornelia de Lange Syndrome Foundation, Inc. or a responsible adult designated by same, to take my child to the nearest physician for, and to consent to, treatment of the child, solely at my expense. I hereby fully release and discharge Cornelia de Lange Syndrome Foundation, Inc., its officers, directors, and agents, and each of them from any and all claims, demands, actions or causes, which may arise out of or is in any way connected with said treatment. I do hereby authorize the Cornelia de Lange Syndrome Foundation, Inc. or a responsible adult designated by same, as agent(s) for the undersigned to consent to any x-ray examination, anesthetic, medical or surgical diagnosis or treatment and hospital care that is deemed advisable by, and is to be rendered under the general or special supervision of any physician and surgeon licensed under the provisions of the Medicine Practice Act, whether such diagnosis or treatment is rendered at the office of said physician or at a hospital.

It is understood that this authorization is given in advance of any specific diagnosis, treatment or hospital care being required but is given to provide authority and power on the part of our aforementioned agent(s) to give specific consent to any and all such diagnosis, treatment or hospital care which the aforementioned physician in the exercise of his/her best judgement may deem advisable.

The dated signature of the child's Legal Guardian is **required** below:

Printed Name of minor(s) _____

Printed Name of Parent and/or Legal Guardian _____

Signature of Parent and/or Legal Guardian _____ Date _____

ACKNOWLEDGMENT OF CHILDCARE POLICY

I acknowledge that I have read the CdLS Childcare Policy on page four and accept the terms of that policy.

Printed Name of Parent and/or Legal Guardian _____

Signature of Parent and/or Legal Guardian _____ Date _____

CHECKLIST:

- Make hotel reservations (see page 2). Be sure to indicate the CdLS Foundation Conference Group Code CDLCDLA.
- Complete registration and relevant forms. Registration is not complete if page 7 is not signed.
- Return registration and payment to 302 West Main Street #100 Avon, CT 06001 or fax to 860-676-8337. If paying by check, make payable to the CdLS Foundation.

You will receive a *Welcome to Conference packet* in early June.

IMPORTANT DEADLINES:

Early Bird Registration: March 26

Regular Registration: May 17

Hotel Reservations: May 25

QUESTIONS?

800-753-2357 or

info@CdLSusa.org



Grow. Transform. Soar.
