

Cornelia de Lange Syndrome (CdLS)
Foundation

Partnership Opportunities

About Cornelia de Lange Syndrome (CdLS)

Cornelia de Lange Syndrome (CdLS) is a rare, genetic disorder present at birth and affecting an estimated 1 in 10,000 live births. Researchers believe upwards of 20,000 people have CdLS but remain undiagnosed.

The severity of CdLS ranges from mild to severe, but most individuals with CdLS share similar characteristics, such as:

- Small Stature
- Joined Eyebrows
- Long Eyelashes
- Uprturned Nose
- and Thin, Down-Turned Lips

Common medical issues associated with CdLS include:

- Severe Gastro-Esophageal Reflux and Feeding Difficulties
- Cleft Palate
- Vision Problems
- Hearing Loss
- Seizures
- Behavioral Issues
- Missing Limbs and/or Limb Differences
- Heart Defects

Most children with CdLS have some degree of intellectual disability. Overall, cognitive and physical development is slowed, while delays in speech and communication are even more pronounced.

About the CdLS Foundation

The CdLS Foundation is a national nonprofit family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS and their families make informed decisions throughout their lifetime. The Foundation serves about 2,800 people with CdLS, 10,000 parents and relatives, and thousands of professionals; as well as approximately 500 families whose child with CdLS passed away.

Throughout the year the CdLS Foundation hold awareness, fundraising and social events. The biennial National CdLS Family Conference and Scientific & Educational Symposium is the Foundation's largest and most well-known event.



About the National Family Conference Audience

97% have a family member affected by CdLS

70% are between 31 and 50 years of age

80% are female

82% own their home

40% have no children under the age of 18

26% bank with a credit union, 10% with Wells Fargo, 9% with Chase

27% drive Honda, 21% Toyota, 18% Dodge

Respondents were most comfortable with automotive, banks, credit card companies and consumer goods as sponsors

93% use Facebook, 57% Instagram, 24% Snapchat as their preferred social media



In the next 18 months...

44% will buy or lease a new vehicle

5% will switch banks

12% will apply for a mortgage

50% will buy sporting clothes/equipment

58% will renovate their home

88% will stay in a hotel

74% will buy airline tickets

40% will buy insurance

74% will book a vacation



Let's Get Digital

Website Traffic: 516,000 page views

Facebook: 3,702 followers

Twitter: 730 followers

Instagram: 1,034 followers



Our Sponsors Matter to our Audience

98% would consider changing a purchase based on corporate support of CdLS Foundation!



About the Symposium Audience

Specialties represented

- Speech Therapy 16%
- Genetic Counselors 11%
- Pediatric 11%
- Gastroenterology 5%

72% are managers/leaders in their respective fields and 53% play a role in decision making

63% have 10 or more employees reporting to them

80% have worked in their field 16 years or longer

47% have operating budgets greater than \$51 million

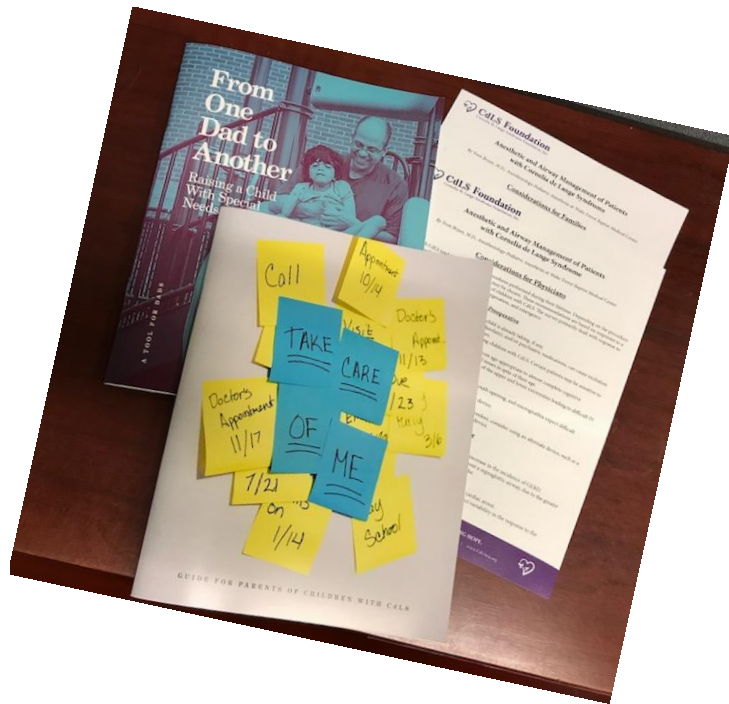
Products they are considering purchasing in the next 12 months

- Database Software 38%
- Research Equipment 38%
- IT Support 31%
- Phone Plan 23%

83% are likely to consider product/service purchases from companies that support the CdLS Foundation



Some of Our Opportunities...



About the CdLS National Family Conference

June 2020

This unique 3-day event draws over 500 people every other year and provides education and support to families of individuals with CdLS. Attendees receive free consultations in multiple medical specialties with experts in a range of fields, they attend a variety of specially curated workshops with their needs in mind and, most importantly, they have opportunities to meet other families facing similar challenges.

Interested in a Sponsor Partnership? Some of the options available are:

- Naming rights for special events, childcare areas, etc.
- Banner or Signage displays
- Speaking Opportunities
- Recognition on Printed and Digital Materials
- Recognition on t-shirts, lanyards and other promotional materials
- And More!



About the CdLS Scientific & Educational Symposium

June 2020

This event happens in the two days prior to the National Family Conference and it brings together physicians in various clinical disciplines, scientific researchers, teachers, and allied health professionals. Through lectures, poster session and formal discussions, attendees will learn about medical and educational issues facing individuals with the syndrome, as well as an update on current basic science research

Interested in a Sponsor Partnership? Some of the options available are:

- Naming rights for VIP Areas, refreshments breaks, networking breaks, etc.
- Banner or Signage displays
- Speaking Opportunities
- Live and Recorded Mentions
- Digital Recognition
- And More!



Golf Anyone?

May and October 2019

The CdLS Foundation hosts two sell-out golf tournaments annually attracts some of our strongest supporters and members of the business community!

New England CdLS Foundation Golf Tournament in Ipswich, MA, May 2019
Missouri CdLS Foundation Golf Tournament in Sunset Hills, MO, October 2019

Contact us for specific proposals to fit your Company's unique needs!

2018 Golf Tournament Sponsors include:

Madison County Wood Products
Pallet Logistics Management
KeyBanc
Craig-Hallum Capital Group
RBC Capital Markets
BMO Capital
Crown Machinery
And More!



We Invite You To Connect With Our Audience!

We're excited to hear about the sales and marketing goals for your organization, and how we can help you achieve them. Everything we do is custom based on your needs – there is an opportunity for every budget.

Some of the activation opportunities we offer include:

- Branding
- Naming rights
- Booths
- Product placement
- Employee engagement
- Leadership and speaking opportunities
- Database Marketing
- Digital Marketing

Tell us what your goals are and we can put something together to help you be successful.



Let's Start a Conversation

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THANK YOU