**2011 Income and Expense Statement**

**January 1 - December 31, 2011**

**Total Net Assets**: 920,630

**Unrealized Gains/Losses**: 44,041

**Surplus/Deficit from Operations**: 6,698

**Total Expenses**: 928,285

**Total Revenue**: 972,326

**Total Support Service**: 109,312

**Management and General**: 49,085

**Support Services**
- **Public Information and Education**: 237,400
- **Family Support Program**: 340,075
- **Research**: 28,790
- **Outreach and Awareness**: 212,708
- **Professional Development, Program Services**: 33,548
- **Nat’l Conference**: 319
- **Program Services Fee/Federated Campaigns**: 479,490
- **Memorial/Celebration**: 77,132
- **Gifts that Count – Clubs and Organizations**: 9,755
- **Direct Mail/Foundation Drives**: 62,335
- **Major Donors**: 217,531
- **Corporations/Company Donations**: 3,781
- **Individual Donations**: 30,371

**INCOME 2011 Audited**

**EXPENSES**
- **Program Services**
  - **Professional Development, Outreach & Awareness**: 37%
  - **Family Support Program**: 26%
  - **Public Information**: 6%
  - **Administration**: 5%
  - Other: 10%

**THE CdLS FOUNDATION FAMILY**

**Offices**
- **Sara Gaffney**: Office Manager
- **Francesca Scognamiglio**: Graphic Designer/Web Master
- **Janette Peracchio, M.Ed.**: Finance Manager
- **Deirdre Summa, M.S.W.**: Family Service Manager
- **Gail Speers**: Development Manager
- **Antonie Kline, M.D.**: Medical Director
- **Marie Concklin-Malloy**: Acting Executive Director
- **PROFESSIONAL STAFF**
  - **Marie Concklin-Malloy**: President
  - **Deirdre Summa, M.S.W.**: Director of Operations
  - **Janette Peracchio, M.Ed.**: Finance Manager
  - **Daniel & Henry Certified Heating & Cooling**
  - **Gibbons Council #2521. Knight of Columbus, Cardinal Special People in Need.**
  - **Odyssey Foundation.**
  - **Mortensen Foundation.**
  - **William and Alice Teixeira family**
  - **RBC Capital Markets**
  - **Madison County Wood Products**
  - **KeyBanc DRIPS**

**THE CdLS FOUNDATION Family**

**EDUCATIONAL ADVISORY GROUP**

- **Roger Woerner, B.S., SpEd.**
- **Anisi Roman, M.Ed.**
- **Lucy Nutt, Ed.S., CCC-SLP**

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The Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure that no family need be alone, either physically or emotionally, as they learn about CdLS, research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS, promote early and accurate diagnosis of CdLS, and to study gene functions.

Our Mission

The Cornelia de Lange Syndrome Foundation is a family support organization that exists to ensure that no family need be alone, either physically or emotionally, as they learn about CdLS, research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS, promote early and accurate diagnosis of CdLS, and to study gene functions.

Our Highlights:

- Family service coordinators facilitated 330 Ask the Expert submissions and connected more than 300 families with one another.
- Volunteer run fundraisers raised nearly $104,000.
- News articles and broadcast stories about CdLS reached an estimated 14 million people in the U.S.
- Facilitated 330 Ask the Expert submissions and connected more than 300 families with one another.
- Additional golf tournaments raised a record $97,000.

Total revenue was down from 2010 due to less of government funding and fewer individual donations, typical in a non-conference year. However, the year ended just $28,000 shy of the $1 million mark. Spending remained in check, with just 11 percent of revenue supporting administrative and fundraising expenses.

We hope you find this annual report informative and that you take a moment to read about some of the "heroes" who go the extra mile to help this organization. If you have an idea or moment to read about some of the "heroes" who go the extra mile to help this organization. If you have an idea or

We are fortunate at the CdLS Foundation to have many heroes in our extended family—all of whom are models for others. Their actions, whether big or small, have a lasting impact on the work of this Foundation. At right, we introduce you to just a few of our heroes.

Volunteer Hero

As a longtime Awareness Coordinator and, more recently, a Regional Coordinator, Felicia Brown-Colbert is an advocate for her daughter Rayven and a support for local parents. She lives just a few miles from the placing of San Francisco's famous Golden Gate Bridge. Along the three-week, 4,700-mile rideHonored the Foundation's longtime volunteer and outgoing board president David Fowler and his wife Susan. The Boston event generated approximately $97,000. The occasion will serve as a model for future events honoring exceptional volunteers and leaders.

Donor Hero

Mary Lou Bransfield's grandson Aiden was diagnosed with Cornelia de Lange Syndrome (CdLS) at age three. "It was important to my family that we find a support system of professional help," says Mary Lou. "When we found the CdLS Foundation, I felt as though we had won the lottery." Mary Lou was grateful for the "warm, caring, understanding, and knowledgeable voice on the other end." She wanted to do something to help, so she started donating to the Foundation monthly—and she continues to do so today.

Board Hero

David Fowler has been deeply involved with the CdLS Foundation since his son Logan was diagnosed with CdLS more than two decades ago. He held volunteer leadership positions with the Foundation on and off since 1992, including time as the president of the Board of Directors from 2005 to 2011. During that time, he was an energetic advocate, leading the Foundation's charge into Washington, D.C., raising awareness of CdLS among Congress that eventually resulted in $238,000 in federal funds.

Sibling Heroes

For two groups of siblings, the 2011 Baltimore Running Festival was truly a family affair. Abbey and Bethany Black, sisters to Alex, and Jennifer and Andrew Vojtecky, siblings to Stephanie, hit the city's streets as part of Team CdLS—Bethany, Andrew and Jennifer in the 5K and Abbey, who was nursing a broken leg, cheering the team on. "It's important to show support for my brother, the city's streets as part of Team CdLS—Bethany, Andrew and Jennifer in the 5K and Abbey, who was nursing a broken leg, cheering the team on. "It's important to show support for my brother, whom I so admire," says Jennifer. "I was able to cheer him on and feel part of the team. It was a wonderful experience."

Event Hero

On June 3, 2011, Ken Fouls finished his cross-country motorcycle trek, Adrian's Ride, in the shadow of San Francisco's famous Golden Gate Bridge. Along the three-week, 4,700-mile ride that started in New Hampshire, Ken raised awareness of CdLS, and funds to benefit the Foundation. The ride was in honor of his 17-year-old grandson Adrian. "As I rounded the final curve to the Golden Gate Bridge, there it was: San Francisco. With tears in my eyes, I looked down at the picture of Adrian that I had been carrying and said, 'We made it. I did it just for you. He will never be able to verbally thank me, but I know he knows what grandpa did for him.'"