



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

## As Different as Snowflakes...

*By Lynn P. Audette, M.S.W., Family Service Coordinator, and Bruce Cleinman, M.A.*

Soon snow will be falling in many parts of the country, reminding us that no two snowflakes are alike. And, like snowflakes, each of us is different in our own ways. Our differences don't diminish us or make us less. They reflect our strengths and abilities. Like snowflakes, each of us is beautifully and mysteriously made. We all have a place in the world and a part to play in it. Some of us choose to fit in with our peers, while some of us choose to march to our own drum.

In speaking with families, we are reminded of the process families experience in addressing their own feelings about CdLS, as well as those of the public. For those with newborns, swaddling and covering is both an acceptable and good means to protect oneself from a world that can be harsh. As parents gain more confidence in managing the questions that may arise when out, they may be willing to have their child be more visible to the world. In thinking about this, we have spoken with several families and have gathered their thoughts to share with you.

### Alexus

Lourdes and Tommie, parents of Alexis, feel strongly that "We are blessed with our daughter, so it doesn't matter how people may feel or think. We would never change anything about her appearance unless it was medically necessary! We dress Alexis as any other parent would dress their child." However, to make things easier for Alexis, who hate to have her hair washed and combed, the family has found a unique way to address this battle. They have her hair straightened or braided weekly at a beauty parlor. This small effort has made an amazing difference to their family.

### Maddy

Kim and Tom are familiar with the public stares and having to field others' questions about their daughter Maddy. "Initially, I believed that people were staring because they thought there was something wrong with her. Maddy has the upper limb defects, a g-button, hearing aids, and now glasses, so there is a lot to notice. At first this was difficult for me to handle. I thought she was beautiful, and when others stared at her in horror, it hurt my feelings. When Maddy was an infant, we stayed home a lot because of her susceptibility to illness." Sometimes others' responses were painful to observe. "I wasn't ready to cope with it, and didn't yet have the tools to handle it, so some of my responses were harsh or inappropriate. Nowadays, I tend to greet others' attention with a smile and a handful of [CdLS Foundations brochures]."

Within families, parents may respond differently to the strangers' stares. Tom took those stares in a completely different context. When he noticed someone giving Maddy undue



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.  
*Reaching Out, Providing Help, Giving Hope*

attention, he would ask them, “Isn’t she beautiful? We love looking at her, too!” Tom feels he’s been more successful with a direct approach, especially with children. “Thanks for noticing my daughter. Can I answer any question for you?” Mostly, he says, people comment on her beautiful hair, how cute her clothes are, etc. he’s also had people come up to talk to him about a child in their life with some type of disability or syndrome, and they just want to connect on that level.

Some families have found, when faced with these situations, that it is often easier to educate children. Kim states, “I always make a point to ask them if they have any questions, or if they’d like to say hello to Maddy. I tell them that she won’t hurt them, that she isn’t angry or upset (unless she IS!) and that asking questions is okay...it’s the only way they will learn anything. Some kids are shy, but others walk right up to Maddy and say hello. Sometimes, she will even wave back to them!”

Like other parents, Kim recognizes that a neat appearance counts. She replied, “I make sure to keep her well-groomed and well-dressed at all times. Her clothing is often adapted to fit her arms (sleeves shortened, etc.). Right now, tome and I are discussing whether or not to lighten or remove her facial hair. I shaved her unibrow a couple of times, but now that she wears glasses, we may not need to continue.”

Lastly, Kim observes that public scrutiny allows her to educate the general public about CdLS, which she thinks is very important. She adds, “At the same time, it allows Maddy to see that I am not ashamed of her. I am proud of who she is and all that she has accomplished, and I think she knows that. We’ll never stay home from an event or activity because others may be uncomfortable with [the ways she looks]. We go out and enjoy ourselves as a family.”

## Michael

Michael was born with only one finger on both hands. His mother Julie has noticed stares from people. It is her felling that they wonder, “Is that the Mom? Did she take something to cause such a birth defect?” she notices that they often look away, but seem to remain interested and would like to know more. “Occasionally you’ll run into someone who just smiles and then just keeps on smiling, to let you know they notice and totally accept you.”

Like the Maddy’s parents, Julie carries CdLS Fact sheets, but parents may not always choose or have the time to educate others about the syndrome. Sometimes Julie avoids small spaces like elevators, because she knows she would have to act friendly and outgoing. She notices that if she’s friendly, people seem to loosen up and act more normal. “It helps to be with a friend or relative too when we’re out. It’s as if to say we’re happy and okay with Michael, so he must be okay.”

Michael’s family shared that they would never change his’s appearance. Julie personally likes his features and is proud of how handsome he is. She tries to keep him extra neat, clean and



# CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

*Reaching Out, Providing Help, Giving Hope*

well dressed. In unfamiliar settings, Julie sometimes chooses to dress Michael in long sleeves to cover his arms until she is somewhere more familiar.

In closing, Julie reflects that it is not always easy and that people can be rude. Fortunately, there are also those who are kind and make you eager to “meet the challenges.”

The Foundation Family has many resources to help make it easier for you to face public situations. We welcome your calls and emails at [families@CdLSusa.org](mailto:families@CdLSusa.org).