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

Raising a Child with a Disability: Welcome to Holland

By Emily Perl Kingsley (From the "Dear Abbey" column)

"I am often asked to describe the experience of raising a child with a disability -- to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It is like this. . . when you are going to have a baby, it is like planning a fabulous vacation trip -- to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas of Venice. You may learn some handy phrases in Italian. It is all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!", you say. "What do you mean Holland? I signed up for Italy!! I am supposed to be in Italy. All my life I have dreamed of going to Italy."

But there has been a change in the flight plan. They have landed in Holland and there you must stay. The important thing is that they have not taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It is just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It is just a different place. It is slower pace than Italy, less flashy than Italy. But after you have been there for a while and you catch your breath, you look around, and you begin to notice that Holland has windmills. Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they are all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that is where I was supposed to go. That is what I had planned."

And the pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss. But if you spend your life mourning the fact that you did not get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland."