

Welcome to Holland Emily Per Kingsley

"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's like this..."

When you're going to have a baby, it's 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 in Venice. You may learn some handy phrases in Italian. It's 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'm supposed to be in Italy. All my life, I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would have never met.

It's a different place. It's slower paced than Italy, less flashy than Italy. But after you've 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're all bragging about what a wonderful time they had there.

And occasionally you might say to yourself "Yes that's where I was going. That's what I had planned". This loss will always be present with you.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, very lovely things about Holland.

From: Tom <treiley2@comcast.net>
Date: April 3, 2019 at 11:18:15 AM PDT
To: "Sen. Jeff Bridges" <jeffbridges@senate.gov>
Subject: Re: PEP

Senator-

I understand you may have reservations about PEP's history of having its Conferences at mountain hotels in tourist off seasons. To understand why these venues have been important to PEP attendees for its 40 year history requires your imagination.

I ask you to put yourself in the shoes of a father of a child with special needs. Your wife has been taking your child to doctor appointments and to IFSP's and now IEP's at school since the diagnosis of cerebral palsy was made 6 years ago 6 months after Johnny's birth. Both of you remain heartbroken, frustrated, sad, envious of other parents, and angry. You've felt obliged to be the breadwinner as your wife must spend so much time with Johnny's birth and no longer works. You joined a sports league to clear your mind. You and your wife have lost both friends and the closeness you once shared. Intimacy is rare, both spoken and physical. You feel lost as you seem to be lacking the tools to "fix" Johnny's problem.

Your wife hears about PEP and how the conference transform parents into effective partners in getting services and educational opportunities for their kids with disabilities. She also hears how vital it is for BOTH parents to come to the conference together, leave the child at home, and attend all sessions.

So, you are a busy guy and you've never left your child for two nights. Hell, you haven't had any trips together with your wife, just the two of you, in 6 years.

What would lure you to change your life and get away for 2 1/2 days to learn about "how the law works for kids like yours and such"? Leaving Johnny with your parents with his CP and seizures sounds crazy. But your wife seems insistent. Then she tells you that food will be provided and that a two nights stay at a hotel far away from home is part of PEP. Might you leave the farm in Eastern Colorado, or your mechanic's job in Denver for that opportunity? Or would a hotel in Denver be the lure? Why then you or the wife could just go home several times a day to check on Johnny.

The historic PEP formula is that of workshops, understanding one's own grief process, learning the law; and attending facilitated intimate small groups separate from one's spouse. But parents and professionals must be enticed to volunteer to attend. Lives are transformed but only by winning programs such as PEP has been for so, so long.

Thus food.

Thus being able to spend the night.

Thus mountain hotel venues DURING TOURIST OFF SEASONS when rooms are dirt cheap and mountain towns need the revenue.

Thanks for your help,

Tom