

Once upon a time...

- **If we take a look at our way back....**
- **How would you describe it?** Contented? Exciting?
Stressful? Moving forward? Holding back?
- There are things we dream of doing one day, there are things we wish we could forget or change...
- **What would your life look like if you could start over again with NO PROBLEMS?**

Who am I?

- I am Oana's mother. She has PWS.
- We have a loving and caring family.
- I am here today with you to tell you my story having a daughter with PWS in Romania and starting the movement for people with PWS and RD in Romania.



When our child was born

1985 – our first child & we were very young

Neonatal hypothermia and feeding problems

Thick saliva

Excessive weight gain after starting eating

Small hands and feet

No crying

Developmental delay

Interest for food





What was suspected before PWS

- Chronic encephalopathy with hypohonia until 18 years
- Cushing Syndrome
- At 8 years, it was the first time when I heard about PWS
- We started a rehabilitation program since she was 6 weeks in Cluj and Dezna, 3 times/ year...
- She started to walk at 2,5 years
- At 3 years she started kindergarden ...
- She finished high school and work with our support

What did doctor say?



- Doctors said that she will remain as a baby for her entire life
- Or that we spend all our energy and money to look for something that does not exist instead of doing another baby
- I don't know what it is. You have anyway to do a lot of rehabilitation to support her to walk, talk and act normally.
- If you want her to be “normal”, you have to ask her as much as from an ordinary child





- No one can be perfect, or have a perfect life. But every one of us has the right to have the opportunity to experience the everyday challenge.
- **Learning from mistakes can't be stolen from anybody!**
- Living with a rare disease is hard, as a rare disease is no more RARE when it affects someone you love and care.
- **Love is part of the treatment!!!**

Rare diseases

1 in 2000 means:

- Isolation
- Loneliness
- Forgotten
- Vulnerability
- ...

LESS HOPE



Rare diseases

**6000 to 8000
different rare
diseases...**

almost NO HOPE



Living together, learning together



We can't imagine a different life...

We really love:

- seeing her doing things which had not been thought possible.
- the loving, funny, caring and kind personality of learning to be patient and tolerant.
- her “own way” to see a perfect world around.



PATIENTS STORIES

WELCOME TO HOLLAND (Emily Perl 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 guide books 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.

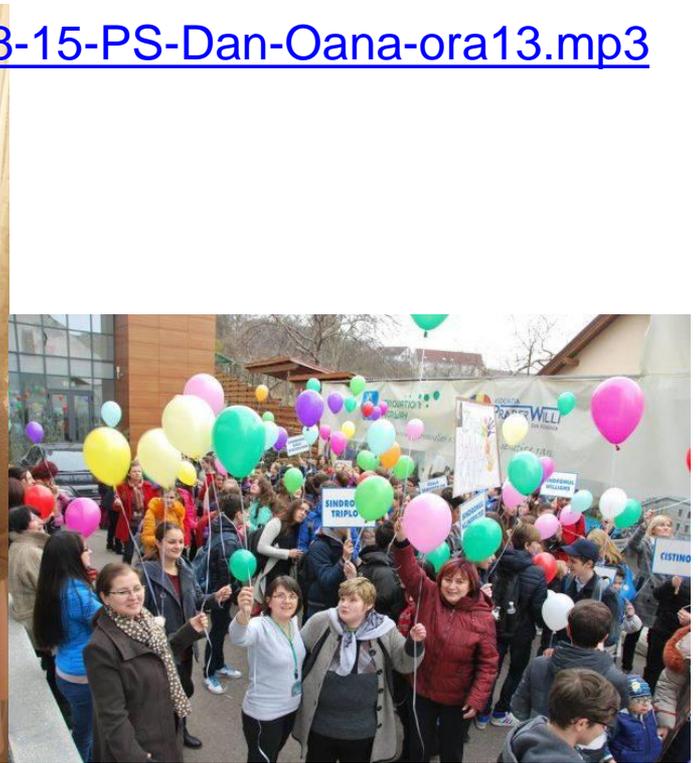
The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just 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....and 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 for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

*.....And the pain of that will never, ever, ever, ever go away...
because the loss of that dream is a very very significant loss.
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, the very
lovely things ... about Holland.*

<http://www.radionoro.ro/sites/default/files/audio/2017-08-15-PS-Dan-Oana-ora13.mp3>



Thank you!



Show Your Rare!
Show that You Care!

A collage of several small photographs showing various scenes: people sitting at tables, a child playing on a stage, a woman holding a child, a group of people outdoors, and a woman with a dog. The collage is set against a blue background.


Asociația
PRADER WILLI
din România