



## Olga Joklová, the Olga Havel Award 2015 laureate:

# “Smile at each other!”



*This year's Olga Havel Award laureate is Olga Joklová (30). She shares her name with Olga Havel and was named after her mother, who has been taking care of her. A coincidence? Most likely not! All three of them are characterized by unusually strong will and indomitable inner strength. “We stand in the front lines,” Olga's mother comments on her daughter's disease. Olga was born with the “butterfly disease” (Epidermolysis bullosa). Her skin is fine and vulnerable as butterfly wings, but her soul is astonishingly beautiful and free. Just like a butterfly in a summer day!*

● **Do you have any idea why the disease chose you? Does it have anything to do with genes, constellation of specific conditions, or just a mere coincidence?**

This disease is genetic, however, my younger brother who had died before I was born was healthy. It hit me probably just by coincidence. Both my parents had the defective gene.

● **Could you describe for those who are not familiar with this disease yet, what bothers you the most, what hurts you?**

Everything hurts. Especially in the past months the pain has been worsening. My whole body is wounded and it causes water leaking, which almost cost me my life because of severe dehydration between November and December 2014. I have blisters everywhere, even in my mouth and oesophagus, and I can't swallow my own saliva.

Because of that I've had a PEG pump for two years, which goes directly to my stomach. My teeth are falling apart, my fingers on hands and feet have been growing together since I was born, and that's why I've been on a wheelchair for the past few years and why I cannot work not even in the household. I often have conjunctivitis and I have a different shape of my inner organs.

● **How can doctors help you when it's an incurable illness?**

There is a great variety of options in curing materials, which don't traumatise skin as much as those 10-20 years ago, when we had only the basic gauzes and even had to wash them. There are also procedures to widen the oesophagus, however, those cannot be repeated too many times since the butterfly oesophagus is very vulnerable and could burst. It's happened to me once with balloon dilatation. And what can help too, is the approach of the hospital staff, which has changed incredibly. This disease is so rare that we, patients and their families, are actually the best specialists, and doctors and nurses are aware of it, willing to accept this fact and communicate accordingly.

● **People with the butterfly disease also receive support from non-profit organisations, don't they?**

Indeed. The most fundamental NGO is the charity organisation Debra ČR, which contacts other foundations and they all help us. (Olga and her mother have been cooperating with Debra for 11 years. She's been an active volunteer spreading knowledge about this disease, for what she's been awarded the Olga Havel Award.)

● **We already know a bit about your pain, although we could hardly say we can imagine how it feels. But what about your joys? What is it that makes you smile?**

I have a stuffed toy family that I play with together with my mom. We imitate their voices :). Actually I love my life although it is so difficult. I've got a bird nest over my window, pieces of art from friends on the wall, I like music, movies, books, nature, travelling, and our true friends, who are currently helping us, calling us and offering support in form of watching over me since I can't be left alone.

● **Does the butterfly disease bring one to friends? Where did you find friends, within** ▶▶

### Question for Olga's mother:



**Olga is 30 years old and you have been taking care of her the whole time. How difficult was it to handle this situation and stay home with your daughter? How did you solve it with regard to finances?**

“The most important was to learn to face the situation. There was no money, the state didn't recognise this disease as a handicap so the first five years I worked at home during the nights. After 1990, the situation improved slightly, but every time we had to request an exemption or mitigation of the harshness of the law. Czech healthcare, thanks to a great enlightenment campaign, gathered information about our disease and worked on the EB centre. There are doctors in regional and local hospitals, who are willing to listen and provide help. Most of the hospital staff learn to work with butterflies and treat them individually. It is about personal interest and will. First we started with washing the already used bandages. Thanks to the NGOs we now have all the needed items and equipment - bandages, ointments, nutrition, and such. We could never afford it all ourselves.

## Special thanks at the Olga Havel Award 2015 was given to:

### ● in Donors category:

**Café de Paris**, represented by Pavel Culek, long-term contributor to the program Senior in form of Beneficial concerts of good will organized by Kocián Šolc Balaščík Law Office

**Vít Melichar** from ČSOB Private Banking – long-term donor, contributes to the purchase of medical aids for people with disabilities

**Blanka Seidlová** – long-term donor to the OHF

**Jiřina Šálená** – together with her late husband have been contributing on a regular basis since the establishment of the OHF

**Emanuel Šíp** – generous friend and donor to the OHF

### ● in Cooperatives category:

**Bohumila Fetterová** from Nižbor u Berouna – teacher, long-term supplier to the OHF and its

gallery with paintings made by children with disabilities

**Ema Rónová**, Astrosat Media, s. r. o. – editor, promoter of the OHF in media

**Jana Jílková** – editor, promoter of health care projects of the OHF

**Anna Freimanová** – documentarist from the Václav Havel Library, cooperates on events in memory of Olga Havel

**Linda Kaucká** from ČSOB – representative for the area of corporate social responsibility at ČSOB

### ● in Outstanding projects category:

**Jiří Herynek** – Ergotep, team of invalids Proseč, for project “Ergotep for students and teachers”

**Jaroslava Jůzová** – Alzheimercentrum Prácheň, o. p. s., establisher of the Prácheň sanatorium,

which has grown into a network of 9 specialised care facilities for clients with Alzheimer disease and other types of dementia

**Vendula Kalusová** – chair of registered association “Na slobode”, which provides aid and support for people after imprisonment, project “Home as a value”

**Jiří Krejčí** – president of the charity organisation TŘI, Čerčany, provider of hospice care in the Central Bohemian region.

**Petr Pašník** – lecturer for directing computers by voice, member of the team Polovina nebe, o. p. s. active within the whole Czech Republic.

**Hana Vojtová** – principal of the Senior Home of Master Křišťan in Prachatice, lecturer of the concept of sensual acquisition according to Lore Wehner – educational program for the Senior Home staff.

## Nominations for the Olga Havel Award 2015

*Until April 17, 2015 individuals and organisations had been registering for nominations for the Olga Havel Award, which is annually being awarded to a public figure, who despite of his or her disability has been helping others with handicap. Six candidates made it to the second round:*

**Václav Fanta** (75), Eyesight handicap, Prague

Art photographer, co-establisher of the Catholic foundation for blind, establisher of a choir for blind people Vokál and current supporter at the R MEDIA agency with creation of charity calendars.

**Olga Joklová, Jr.** (30), Butterfly disease (epidermolysis bullosa congenita), Jihlava  
Volunteer at NGO DEBRA ČR, which helps to improve quality of lives of patients with the butterfly disease. She has been active in an enlightening campaign about this rare disease for years.

**Daniela Kelišová** Tumor, Prague

Chair at association ALEN (civic society of women with breast cancer) helps ill women to get through the physical and mental difficulties with regard to oncological procedures, supports their interests and needs in society, takes care of

their knowledge regarding the illness, remains active in social and legal field.

**Milan Linhart** (61), Physical and eyesight handicap, Ostrava

M. Linhart suffered a severe accident during his military service, what resulted in spastic quadraparesis and basically loss of sight. He is a historian of Art, chair of the Club of Czech tourists with eyesight handicap. For 25 years he has been actively working for organisations for people with poor eyesight and the blind. He's been engaged in eliminating the barriers in public and integration of the blind into society.

**Petr Pašník, DiS.** (34), Cerebral Palsy, Prague

For four years has worked for the Association for complex care of cerebral palsy of children, now he is a member of the team Polovina nebe, o. p. s. – provider of social services, where he works as IT expert, specialising on voice technologies (voice control of computers).

**Václav Ptáček** Deaf, Prague

The oldest lecturer of the Czech sign language in the Czech Republic, co-author of the Czech Language dictionary (book and DVD), closely cooperates with the University in Olomouc, cooperative on the reading machine for public transport, which helps the deaf people when travelling.

## “Smile at each other!” completing the interview

### the hospital staff or patients, or maybe people you met otherwise?

During my childhood I've always been with healthy children. I was an adult when I started to meet people with the same illness through Debra. But friendship isn't about disease, it's about the spark or belonging to each other. Our friendships, it's actually a destiny!

### ● You, Olga, have been standing on the edge, which people are afraid to cross, for years already. Is it possible to face the fact, that one day you will have to take that step? What do you have in mind with regard to this?

I understand that my life is somehow limited all the time. This year I already turned 30. As a child I was horribly scared of death,

and now we are all trying to postpone it as much as possible. I don't want to leave my mom alone, although it gets more difficult to take care of me and she is getting older. But we are interconnected to a great degree. I'm scared, but still able to live, not only survive.

### ● Does faith help you?

I actually don't even know. Faith is an interesting thing. When I feel hopeless I say “Oh, God”, but when I really need help, I call mom.

### ● Is it helping to help others with the same disease, people walking on the same path?

Enlightenment and creating new paths in the legal system is a self-realisation that I wouldn't feel otherwise. It is difficult, but it is important. And it gets harder day after day.

### ● Despite of your disease, people call you smart, funny, with a sense of humour. What's

### your recipe for positive mood?

Be crazy! Do not follow the same old ways, rebel responsibly!

### ● Do you have any personal specialty (quote, proverb, talisman), which helps you during the hard times?

I've got my mom. Those who know her cannot forget her and need to smile every time they think of her.

### ● What's your message to the people with handicap?

Handicap is a disaster and not a punishment. The more it pushes the more you learn to bear until you can even laugh at it.

### ● Would you like to add anything else?

Smile at each other! Anytime, anywhere. Pass it on 😊!

Thank you for the interview. ●

Irena Šatavová, photo: Alex Macciani