

With a heartfelt welcome I would like to greet all participants of the „International DEBRA-Conference. My name is Elke Hartig, I shall soon be 41 years old. For such a long time I have been living with the consequences of a dystrophic Epidermolysis Bullosa, subtype Hallopeau-Siemens. My own personal relationship with Stuttgart and the “Paritätischer Wohlfahrtsverband – Parität kreativ-“ has to be seen in connection with my employment as a social worker at our first –and back then very modest- “IEB-DEBRA” office and advice centre which we founded 1989/1990 at the social centre of the “Paritätischer Wohlfahrtsverein”. Back then our organisation included less than a 100 members – counting affected members as well as sponsors. Today we have a little more than 300 members in Germany.

Which words will I, as a person affected by EB, chose for the opening of such an extensive conference as the one which is lying ahead of us during the next one and a half days? Or should it be **you** asking **me** questions, what I should say and as a person affected by EB must say? But what may I say and what challenging contribution can I make for the start?

Here we are, because we exist – initially as human beings living with EB! Otherwise there would be no cause for us to meet or to find ourselves here in such a constellation. I am saying this partly with a kind of painful melancholy and when I say painful I **really do mean the painful part** of the courage and the acceptance, the “YES!” it needs to live a life with EB. Simultaneously I am saying this with an enormous amount of thankfulness in my heart, for our existence.

Firstly we exist as affected persons! (We are specialists, but one usually calls us patients...) But secondly I am most thankful that all of us here exist as scientists, as specialists of research, medicine and care, as social workers, accompanying friends, staff working in various network-groups and administrations. This is where we are inter-dependant on a basis of mutual trust and cooperation, imaginative exchange and sensible offers of help. Thirdly I am very happy, that we exist as parents, siblings, friends and family members sharing life together!

No matter to which category of participants you belong, I want to give a warm welcome to all of you!

Dear conference members, dear guests, allow me, as a person living with EB, to add a few critical comments worth thinking about. Furthermore I hope that these thoughts will remain in our conscience not only for the duration of the conference, but also help to build a base for our future actions and continue to remain at the forefront of our consciousness.

How does a person affected by EB feel, when a significant branch of the scientific community, for example within the prenatal diagnosis, shows an open tendency towards classifying the unworthiness of a developing life, therefore denying the legitimacy of life in case of sickness? How do affected people, mothers, respectively parents, who have been advised in such manner cope with their wounded souls after an abortion (please note the word combination of pain/soul and wound)? Often they are left alone with their pain - the topic itself is problematic and consequently it is hushed up.

On the other hand, what an enrichment, in the past and in the present for families of patients with EB who are and have been experiencing, who were and are able to face the pain and who dared to embrace life in its many-faceted way. Why do aspects of giving and taking, loving and sometimes even hating, of fighting and gaining, to be patient, to argue and to reconcile, to cry and to laugh, of suffering exist and –because of the suffering- to enjoy the more and **all must belong!** People affected with EB and their families often develop personalities capable of weathering many storms!

Last but not least: How fulfilled, holistic, life-embracing people living with EB can be, learning about themselves, knowing and feeling themselves accepted and valued, not to mention the values we acquire as seemingly healthy partners!

Please, ladies and gentlemen, dear friends, let us communicate! Let us talk! There are so many treasures among us, so many wonderful things to discover among the various subjects and terms of reference at this conference.

In conclusion I would like to add a few words concerning the motivation to help and serve each other: help in the classical and “healthy” sense – I am using the word “healthy” on purpose here - , should be “help to self-help” only and should

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3

translation by S. Daby

enable the addressee to lead an independent life. Even though the person may be in need of help and care, this **is** possible! To ask for help and to accept help is not a sign of weakness, but a sign of psychological, emotional and social competency! In many ways humans are not able to become independent, because we are inter-dependent on each other, we are in an inter-relationship to each other and need each other in many ways – this is the meaning of **REAL LIFE**.

In this light even the positions of one giving and the one receiving help can be exchanged, a seriously ill human being can become a teacher for his entourage.

Within the frames of this connection grows the responsibility of scientists, if they want to orientate themselves towards and proclaim a line of respect for life itself and respect for every –however restricted or limited- form of life as worthy and worth protecting. Therefore I hope for scientists to develop a human approach and the gift to come up with ideas towards helping existing life, as it was created by God.

Last but not least it is a personal wish right from the bottom of my heart to put the forthcoming hours of professional-scientific as well as private exchange as well as our social get-together later on under the blessing hands of God, our Creator!

Thank you very much for your attention.

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