

Light from Dark: Using photography to transcend global boundaries



Summary

The Light from Dark project challenges directly social convention which suggests we must not stare. By creating dramatic images through placing subjects, all of whom are affected by rare conditions, on a stage and under a single theatrical spotlight it says, 'look here yes please stare.'

The premise being that its only when we get that engagement, that can we begin the process of education. We forego the time served social graces to capture the world's attention.

The project

The concept for Light from Dark began in Scotland with photojournalist Graham Miller who had worked with vulnerable groups for ten years. His proposal then was to literally shine a light directly on subjects, all of whom were affected by Rare Conditions, and say to the world, look, you can't ignore this anymore it's in the spotlight.

A test shoot was conducted at the MacRobert Arts Centre in Stirling, Scotland on a theatrical stage with Holly, a young girl, affected by Neurofibromatosis with Type 1 deletion. The aim being to test lighting combinations to ensure that the final effect was dramatic but that it did not create frightening shadows or cause stress to those who were being photographed.

Satisfied that this could be achieved a profile of the project was created which was circulated to families working with Einstök börn. No pressure was applied and the invitation left open at which point nine families came forward.

Some examples of the photographs are shown here others can be seen at www.photohonesty.org.

All involved had their hearts melted as Freydis, who has Williams Syndrome, came from direct sunlight into the darkened theatre, looked at the ceiling and said, 'Rúmið hennar' It's bed time.

Conclusions

The process of engagement with families who are very often ignored by society is already a useful. Photography brings with it an intensity of gaze and focus which embraces those who are willing to participate. Most would assume that the instinct would be to hide away and yet many families were willing to be photographed and to open their lives to closer scrutiny to help others understand and, in turn, to be more sympathetic.

Whilst we would not wish to overstate it, the photographer Graham Miller, also noticed that there was something of a cathartic effect on the families. 'It's something I've observed over the years that I've photographed those who are vulnerable. Stigma suggests that those who are affected are somehow less worthy and don't merit attention. Through the intense focus of the camera lens there seems to be a challenging of that view and those who are photographed also seem to get a great deal from the process' says Graham.

It's only when the work is exposed to the public, and less so within the sympathetic environs of this congress, that its true impact can be measured and so there is an intention to exhibit large images in a shopping mall in Iceland. It will be interesting then to gather feedback from the public as they view the work.

As we all know Rare Conditions affect children and families the world over and so this work transcends global boundaries. It is also hoped that this poster can act as a catalyst such that the work gets more exposure, and that more global collaborations can be established.

Acknowledgements

Heartfelt thanks to all the families who came forward to participate in the project.

Thank you to the National Theatre of Iceland and MacRobert Centre in Stirling, Scotland who graciously allowed us to use their stage at no charge and assisted with lighting.

Unique Children in Iceland

Einstök börn (Unique children) is a support group in Iceland for children with rare diseases. The group was established in March 1997 by the parents of 13 children who had no other support group to go to. Today there are over 300 families in the group. The Icelandic population is small so most of the children suffering from rare diseases are isolated, with usually only one or two children suffering from each disease.

Since most of the children in Einstök börn spend long periods of time in hospitals, one of the group's main concerns is to establish a good and prosperous relationship between parents and healthcare professionals to make them aware of our unique needs within the healthcare system.

Our future goals are to keep strengthening the group from within and increasing awareness of rare disorders in our society. We aim to make sure that people have access to understandable information about their diseases, and we want to make sure that in Iceland there will be a database collecting information on rare diseases that will give us a chance to participate in gathering and sharing information within Europe and the world.

We want to make sure that people have access to understandable information about their diseases and to educate the society. Our major focus is to strengthen the group from within; to unite parents and patients with rare diseases.

Einstök börn can be contacted through email, einstokborn@einstokborn.is

Address: Háaleitisbraut 13, 105 Reykjavík, Iceland.

Tel: +354 568 2661

Website: www.einstokborn.is

The photographer

Graham, 56, lives in Perthshire with his wife of 33 years. He has two grown up daughters. He is a photographer with a day job. He has an MA in Documentary Photography and Photojournalism from the prestigious University of Arts London (UAL), ranked 6th in the world for arts and design.

He is currently setting up a new organisation aimed at chronicling and archiving original photojournalism around the theme of vulnerability. The new company will be a Social Enterprise called Really Real Resources which will licence images, which show life as it 'really' is, to global media and third sector. RRR's logo is Graham's terrier Dave because "he's non-judgmental and his love is unconditional. How else to better represent a business whose ambition is to contribute to a world where everyone is viewed equally, free of stigma and prejudice."

Concepts and images copyright Graham Miller

"Breki, 13 years old, was the first Icelander ever to be diagnosed with the CFC syndrome. He practices swimming and gymnastic, loves ball games and cycling (tricycle)." Anna Kristin mother of Breki.

"Bryndís Emma, 6 years old, has a rare chromosome disorder called Cri Du Chat or 5p-. She is very hyperactive and fun to be around, her feelings swing a bit from happy and crying, but most of the times she is happy! She has trouble with speech and balance and social interactions." Harpa Dís mother of Bryndís Emma.

"Emma has Rett Syndrome and is now currently being trained to use her eyes in communication through eye gaze computer technology, which shows really good progress and gives us high hopes of maybe knowing more about what she wants, prefers and likes in the future. All in all, she is a very healthy girl, quite good balanced and smiles a lot. She definitely brings us happiness everyday." Hafdís mother of Emma.

"Snorri Steinn is a leader of happiness, he is a great humourist and has a degree in making people laugh. He has one of the most beautiful hearts I've ever experienced and cares for everyone." Svanhildur mother of Snorri.

Authors

Guðrún Helga Harðardóttir, CEO of Einstök börn*
Guðmundur Björgvin Gylfason, COB of Einstök börn
Graham Miller, Documentary Photographer

