# A Mother's Courage: Talking Back to Autism

A documentary by Fridrik Thor Fridriksson



35mm/HDCAM/DigiBeta, 103 minutes, 2010 Aspect Ratio: 16:9 Audio: L/R stereo

www.amotherscourage.org



# First Run Features

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## **SYNOPSIS**

Imagine not being able to engage with the world around you. Imagine not being able to express your feelings, dreams and aspirations to anyone. Imagine having to depend upon the assistance of others with every mundane task, like dressing or feeding yourself. Imagine living with all of these limitations despite being of sound mind, aware of everything that is going on around you but incapable of letting anyone know.

"A Mother's Courage" is a documentary by director Fridrik Thor Fridriksson which tells the story of Margret, a mother who has done everything in her power to help her severely autistic eleven year old son, Keli.

Although Margret holds no unrealistic aspirations for Keli, she has a quenchless thirst for knowledge about the mysterious and complex condition that autism undeniably is.

On a course set to include the United States and Europe, Margret meets with scientists in the field of autism and autism therapies. Along the way, she meets with other parents of autistic children to hear their unique stories about how they too have been touched by autism and who, likewise share her passion to break down the wall between the children and the surrounding world.

Margret's journey becomes more dramatic and life changing than she had envisioned when she catches a glimpse of hope that her son can be helped to a larger degree than previously assumed.

Perhaps it is possible to break down the wall of autism and get to know the individual behind it.

"A Mother's Courage" is narrated by Academy Award-winning actress Kate Winslet.

# **DIRECTOR'S STATEMENT**

"As a film director, I have always been strongly drawn towards projects that explore the people who society often considers to be "marginal". My films White Whales (1987), Children of Nature (1991), Angels of the Universe (2000), Niceland (2004) and most recently Mamma Gogo (2010) all set out to explore those "marginalized" people who don't quite fit into ordinary life. When I worked on *Niceland* I got to know some of the autistic people who were acting in the film. Impressed by their optimism and honesty, I promised myself to take a closer look into "their world" when I had the time in the future. I was convinced there was more to this subject than what we covered in *Niceland*. Therefore when Frontier Filmworks approached me and suggested that I direct A Mother's Courage: Talking Back to Autism, I immediately recognized what a valuable opportunity the experience would be. I began my work on the film by researching the conditions of the autistic people in Iceland. I found the situation frustrating and depressing to say the least. The struggle that these people and those closest to them are facing is unacceptable. Their situation is all the more shocking because it is taking place in such a well off society like Iceland. I believe that people; politicians and citizens alike have been misinformed about the condition of autism in the past. In my opinion this film will deliver valuable information and raise much needed awareness about the disorder."

- Fridrik Thor Fridriksson

# **ABOUT THE FILMMAKERS**

### Fridrik Thor Fridriksson - Director

Fridrik Thor Fridriksson is a self-educated filmmaker who has made more films, either through his role as a director or producer, than any other Icelandic filmmaker. Fridrik's films are both very personal and deeply rooted in Icelandic culture. His films are often about those who find themselves on the borderline between traditions of the past and the present times. Fridrik's professional film career began with three striking and original documentaries in the 1980's. In 1991, his big international breakthrough came with Children of Nature (1991) which was nominated for an Oscar as Best Foreign Language Film in 1992. Described by the director as "a road movie about old people" it tells a touching love story of two elderly people who wish to return to their roots before they die. No other Icelandic film and very few Scandinavian films have ever attained the international fame and acclaim that Childrenof Nature has garnered. It has received no less than 23 international prizes. Half of Iceland's population has seen Fridrik's feature film Angels of the Universe (2000), a soulful, poetic, and brave emotional tale of the ravages and lonely imprisonment of mental illness. The film had its international premiere at the Karlovy Vary International Film Festival, was awarded the main prize of the FIPRESCI jury (the International Association of Film Critics) and received a special mention from the Grand Jury. In November 2008 Fridrik received the Honorary Edda Award for outstanding achievement in the film industry in Iceland.

# Margret Dagmar Ericsdottir - Producer

Margret Dagmar Ericsdottir is a Business major with an MBA degree from the Florida Institute of Technology. For years Margret had a very sucessful career in business and held various executive positions in Icelandic companies. In 1997 Margret's youngest son Keli was born. Soon after his birth it was apparent that something was not right and Keli was diagnosed as being severely autistic at the age of four. The sudden and profound changes in her family prompted Margret to shift her focus from career-related pursuits to caring for Keli. Margret has dedicated her time and effort to pursuing different treatments in the hope of bettering the life of her son. Her determination to help Keli and other families with autistic children led her to make a documentary film about autism. In 2006 Margret founded Frontier Filmworks, an Icelandic film production company whose goal is to make films that can create a real and lasting difference in our world. Drawing on her experience as a mother of an autistic child, Margret sought out the world's leading experts on autism, as well as families who, like her own, have children stricken with autism. The documentary, entitled A Mother's Courage: Talking Back to Autism follows her remarkable journey which explores autism and will hopefully help to spread awareness on the syndrome. A Mother's Courage: Talking Back to Autism is the first of many similar film projects that Frontier Filmworks is planning.

### **Kristin Olafsdottir -** Executive Producer

Kristin Olafsdottir is the owner of Klikk Productions, a company which specializes in the production of art in various forms and disciplines. She has directed and produced documentaries, feature films and plays. Among Kristin's main projects are the documentaries *How Do You Like Iceland?* (2003) and *Love Is in the Air* (2004), the

critically acclaimed feature length films *Children* (2006) and *Parents* (2007) and the theater production of Vesturport's *Romeo & Juliet* (2004) at the Young Vic Theatre in Britain. Kristin was also the assistant-director of the play *Love* which premiered at the City Theatre in Iceland in 2007. The play became an instant hit and was staged again in 2008 at the Hammersmith Lyric Theatre in London. Kristin graduated from *London School of Economics and Political Science* with a MSc. degree in International Relations in 1999. Kristin has extensive job experience including her work as a producer and TV host at the Icelandic National Broadcasting Service and Channel 2 in Iceland as well as freelance work for Music Room CNN and Channel 6 in Russia.Kristin has made substantial contributions to various charities, focusing mainly on those whose goal is to better the lives and conditions of women and children around the world. Kristin is the guardian of the National Committee of UNIFEM in Iceland and was in charge of UNIFEM's fundraising campaign, The Butterfly Week, in 2008. The total funds raised in Iceland during the campaign resulted in one of the largest single ontributions by a National Committee in the history of UNIFEM.

### John Purdie – Associate Producer

John Purdie, long time documentary producer at the BBC and executive producer of documentaries/Fictual Dramas also at the BBC. John has won 2 British Academy Awards (BAFTA) and several other major awards for his work as a documentary filmmaker. A distinguished career as a staff Producer with the BBC ended with John as Executive Producer of the corporation's Factual Drama Unit. Following this he left to join Antelope Films in the independent sector. He now has his own company WESTERN EYE.

# WHO'S IN THE FILM

(In Alphabetical Order)

Dr. David G. Amaral - was named the Beneto Foundation Chair and Research Director of the M.I.N.D. (Medical Investigations of Neurodevelopmental Disorders) Institute in 1998. The M.I.N.D. Institute is dedicated to understanding the biological bases of autism and other neurodevelopmental disorders with the goal of developing preventative measures and innovative treatments. Dr. Amaral was a founding member of the M.I.N.D. Institute and has been charged with guiding the overall research mission of the Institute. Dr. Simon Baron-Cohen is Professor of Developmental Psychopathology at the University of Cambridge and Fellow at Trinity College, Cambridge. He is Director of the Autism Research Centre in Cambridge. He holds degrees in Human Sciences from New College, Oxford, a PhD in Psychology from UCL, and an M.Phil in Clinical Psychology at the Institute of Psychiatry. He held lectureships in both of these departments in London before moving to Cambridge in 1994. He is also Director of CLASS (Cambridge Lifespan Asperger Syndrome Service), a clinic for adults with suspected AS. Lori and Jason Collins - are parents of five children; their three eldest, all boys, have been dignosed with autism. Lori says that the boys having autism has made her a better person. Her sons teachers and therapists work tirelessly for the boys and share with her and Jason even the smallest victories. Life with three severely autistic boys is hard, Lori says, but they make sure to surround themselves with positive, strong people who shower their family with love. Her sons have taught her to appreciate every victory in life no matter how small.

**David Crowe** was thirty years old when his son Taylor was born. After Taylor's descent into autism at age three, David's life became a journey through the evolving emotions of disbelief, grief, acceptance, understanding, commitment, then fulfillment and happiness as he learned how to become the parent of an individual with autism. Along the way David discovered the value of facilitating peer friendships for children with autism and how to build community-based support for his son.

**Taylor Crowe** was a seemingly normal child until a profound regression into autism at age three. He slowly progressed from a young child who was given virtually no hope to a refreshingly independent young adult who recently completed his studies in Character Animation at CalArts. Taylor's is not the story of a "miracle cure" of autism. He explains that he still struggles daily with the challenges of autism, but emphasizes that by growing up in a nurturing and positive environment he learned that his life was one of capability, not disability. He describes his autism as an "inconvenience," not a handicap. **Dr. Geraldine Dawson -** became Autism Speaks' first Chief Science Officer in January of 2008. Prior to joining Autism Speaks, Dr. Dawson was Professor of Psychology and Psychiatry at the University of Washington and Founding Director of the University of Washington Autism Center. While at the University, Dr. Dawson led a multi-disciplinary autism research program focusing on genetics, neuroimaging, diagnosis, and treatment. Dawson's own research has been in the areas of early detection and treatment of autism, early patterns of brain dysfunction (electrophysiology), and more recently, development of endophenotypes for autism genetic studies.

**Dr. Temple Grandin** - is a professor of animal science at the State University of Colorado and is one of the most accomplished and well-known adult with autism in the

world. She is the author of numerous books on autism such as the US bestseller *Animals in Translation*. Dr. Grandin did not speak until she was three and a half years old. In 1950, she was labeled "autistic," and her parents were told she should be institutionalized. Even though she was considered "weird" in her young school years, she eventually found a mentor, who recognized her interests and abilities, which she later expanded into becoming a successful livestock handling equipment designer, one of very few in the world.

Lisa Helt - is a mother of an autistic boy, Mitch who is non-verbal. She says that when she and her husband discovered HALO Clinic in 2004, their lives changed. Mitch saw Soma Mukhopadhyay, the co-founder of HALO for the first time when he was 9 years old. He had been learning his ABC's and 123's at school, but not with Soma. Soma gave Mitch the communication and education that he never had. Now at age 12, he is mainstreamed in 7th grade and getting A's using Soma® Rapid Prompting Method (RPM). Lisa Helt works as a treasurer and volunteer at HALO.

**Portia Iversen** - is an autism advocate and published author (*Strange Son*) who has dedicated her life to bringing parents and scientists together to speed research work in the field of autism. Portia Iversen, an Emmy Award-winning art director, has been an advocate for autism research since her son Dov was diagnosed with the condition in 1994. Together with her husband, Jon Shestack, she established the Cure Autism Now Foundation (CAN), one of the largest nongovernmental funding resources for autism research worldwide.

**Linda Lange** - earned her bachelor's in journalism from the University of Texas in Austin. Prior to her children, Madison 1996 and Olivia 1999, Lange worked in public relations and design for Schreiner University, while volunteering and serving on the boards of several non-profit organizations. In 2004, she founded HALO – Helping Autism through Learning and Outreach. Since her departure from HALO, Lange says she continues to work with her children, while looking towards developing new opportunities for Madison and her peers with autism as they enter adulthood.

**Dr. Catherine Lord** - is the Director of Autism and Communication Disorders Center at the University of Michigan (UMACC). As Director of UMACC, she provides clinical evaluations and consultations and trains university students and professionals in the diagnosis of ASD. Current projects include the development of a toddler module for the ADOS; organization of the Simons Simplex Collection, a repository of cell lines and phenotypic data for families with a child with autism and a typical child; the development of a measure of spontaneous, functional language in children with ASD; two studies of different interventions with very young children; and a longitudinal study of children followed from age 2 who are now in their teens.

The Meulemans family - say that life is extremely challenging for them having three young sons diagnosed with autism. Even so, they feel they can appreciate and celebrate each and every small step that their three boys accomplish better than any average family. Lilly, their youngest has been tested many times for autism, and it is obvious now that she does not show any signs of the disorder. The family is fund-raising for a service dog for the boys at this time to help them feel safer at home and in the community, as the boys struggle to understand dangerous situations.

Dr. Joseph E. Morrow - is a licensed psychologist, board certified behavior analyst and

a long time professor of Psychology and Behavior Analysis at California State University ,Sacramento (CSUS). Dr. Morrow is the co-founder and President of ABC, Inc. (AppliedBehaviour Consultants) and has over 25 years of teaching experience at the University level. Dr. Morrow has taught a behavior analysis curriculum and has presented internationally in the areas of experimental analysis of behavior, applied behavior analysis, verbal behavior theory and the behavioral/educational treatment of children with autism.

Soma Mukhopadhyay - is the Director of Education for HALO (Helping Autism Through Learning and Outreach) in Austin, Texas. Soma had no formal training in autism before she had her son, Tito, who was diagnosed with severe autism at three years of age. She developed her own intensive educational curriculum that included reading textbooks, teaching him to point to numbers and letters, and giving him age- appropriate education (Rapid Prompting Method). In 2001, Soma came to the United States through a fellowship to try her teaching method at a school in Los Angeles. She relocated to the HALO clinic in Austin, Texas in 2004 where she has refined her trademark Rapid Prompting Method while instructing over 700 students with autism and similar disorders throughout the world.

**Tito Mukhopadhyay** - was diagnosed autistic when he was three and half years. His mother, Soma Mukhopadhyay developed her own intensive educational curriculum, RPM (Rapid Prompting Method), that included reading textbooks, teaching him to point to numbers and letters, and giving him age appropriate education. Tito began to write his creative work from the age of six. He is now 20 years old and a published author of four books.

**Dr. Sally Rogers -** is a professor and the M.I.N.D. Institute and specializes in conducting research into autism and other developmental disorders and treating patients with developmental disabilities, especially young children with autism and their families. Dr. Rogers studies early social, cognitive, and emotional development, development of motor skills, communication, imitation, and language in children with severe disabilities, development of social relationships in people with disabilities, and treatment efficacy in autism.

Jonathan Shestack - is a father of an autistic son an autism advocate and a celebrated Hollywood producer. Along with his wife, Portia Iversen, they founded CAN (Cure Autism Now) in 1995. In its 12-year history, CAN contributed more than \$39 million to autism research and education programs, established a federal advocacy initiative which led passage of the Children's Health Act of 2000 and Combating Autism Act of 2006, and raised the profile of autism through celebrity outreach and grassroots initiatives. Jonathan Shestack joined the board and executive committee o Autism Speak in February 2007, following the merger with Cure Autism Now (CAN).

Candace Smith - was a Colorado high school teacher for twenty-six years. In 1995 she met her future husband, Nobel Laurate Vernon Smith. Since 2003 Candace has assisted Vernon in his professional outreach and in 2006 she assumed a role at with the International Foundation for Research in Experimental Economics, a foundation founded by Vernon in 1997, as the Assistant to the President. In 2007, she continued her pro-bono assistance in the role of Vice President.

**Dr. Vernon Smith** is a Harvard Ph.D. and a professor of Economics at Chapman University. He was awarded the Nobel Prize in Economics in 2002. He has authored or

co-authored over 250 books and articles on finance and experimental economics. Vernon is without a doubt an extraordinary person with extraordinary achievements that he attributes to traits that some say are associated with Asperger's.

**Thorkil Sonne** founded The Specialists in 2004 which is the first market-driven company based on the special talents of people with autism. The Specialists performs software testing, data entries and reviews at market terms for leading companies. Thorkil received the 'Autism Award 2004' by Autism Denmark and 'IT Award 2008' by the Danish IT Industry Association. The Specialists received the 'Network Award 2005' by the Danish Network of Business Leaders and the 'Best Large Social Firm Europe 2006 Award' by The European Confederation of Social Firms.

**Brenda J. Terzich** - holds a master's degree in psychology with a concentration in behavior analysis from CSUS and is a board registered psychological assistant. She is cofounder and Vice- President of ABC, Inc. (Applied Behaviour Consultants) and has been an officer of the California Association for Behavior Analysis. Ms. Terzich has over 20 years of extensive clinical experience in the behavioral treatment of Autism/Autistic Spectrum Disorder, in home and classroom settings.

# **PRODUCTIONS COMPANIES**

### FRONTIER FILMWORKS

Frontier Filmworks, founded in 2006 by Margret Dagmar Ericsdottir, is an Icelandic film production company whose goal is to make films can create e a real and lasting difference

in our world. A Mother's Courage: Talking Back to Autism is the first of many similar film projects the company is planning.

For everyone working at Frontier Filmworks, the work does not stop with the film's release. Many helping hands are needed to carry on the momentum that powerful and meaningful films can create. For those at Frontier Filmworks, this can mean anything from donating time to raise awareness, raising funds and ultimately trying to raise hope for an improved society.

### KLIKK PRODUCTIONS

Klikk Productions was founded by Kristin Olafsdottir in 2002 and specializes in the production of art in various forms and disciplines. Among projects produced are the documentaries *How do you like Iceland?* (2003) and *Love Is in the Air* (2004). Klikk Productions also produced the critically acclaimed feature length films *Children* (2006) and *Parents* (2007) and the theater production of Vesturport's *Romeo & Juliet* (2004) at the Young Vic Theatre in Britain.

# **REVIEWS**

- "A mystery replete with miracles! Will leave audiences stunned and rethinking what has long been considered a disorder devoid of hope."
- John Anderson, VARIETY
- "Nobody is left unaffected by this cute little boy called Keli and his mother's determination to get to know him better."
  - Ingibjorg Rosa Bjornsdottir, ICELAND REVIEW

# **FULL CREDITS**

A MOTHER'S COURAGE: TALKING BACK TO AUTISM

(formerly "The Sunshine Boy")

Produced by: Frontier Filmworks info@frontierfilmworks.com

In Association With: Klikk Productions

Director: Fridrik Thor Fridriksson

Executive Producer: Kristin Olafsdottir

Producer: Margret Dagmar Ericsdottir

Associate Producer: John Purdie
Narration: Kate Winslet
Director of Photography: Jon Karl Helgason
Editor: Thuridur Einarsdottir

Music: Sigur Ros

Björk

Genre: Feature-length documentary

Running Time: 01:43 Language: English Aspect Ratio: 16:9

Formats: 35 mm / HDCAM /Digi Beta Audio: Dolby digital / L&R stereo

Production Format: HDV

Sound Mix: Kjartan Kjartansson

Digital to Film: The Engineroom Reykjavik / Nordisk Film Oslo

Filming Locations: Iceland: Gardabaer.

California: Hollywood, Visalia, Orange, Sacramento, Valencia.

Colorado: Fort Collins. Wisconsin: Greenwille. Washington: Seattle.

Texas: Austin.

United Kingdom: Cambridge. Denmark: Copenhagen.

Unlocking an autistic mind

A feature-length documentary about autism by the Academy Award-nominated director **Fridrik Thor Fridriksson**. Narrated by Academy Award-winning actress **Kate Winslet**.

http://www.amotherscourage.org/