



# POSITIVE EXPOSURE

The spirit of difference

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# INTRODUCTION

POSITIVE EXPOSURE is a 501(c)(3) organization that provides the opportunity for participants and audiences alike to challenge stigma associated with difference, by celebrating the beauty and richness of human diversity.

The organization is a unique partnership between visual arts, genetics, mental health and human rights driven by former fashion photographer Rick Guidotti and Diane McLean MD, PhD, MPH

Rick Guidotti  
POSITIVE EXPOSURE



***“The men, women and children suffering from genetic diseases live trapped in a particular hell - they face ferocious uncertainty, fear of disability and death, and a segregating difference. Positive Exposure not only introduces to the world the stunning beauty of the ‘affected individual’, but also engages the participant in a process that elevates their self-esteem for life.”***

Sharon Terry MA, CEO & President, Genetic Alliance.

Insults, fear, discrimination and hatred based on genetic, physical and behavioral differences plague our society. POSITIVE EXPOSURE attacks public fears about difference with positive images and powerful life stories.

Utilizing photography and video interviews, our educational, training and multi-media exhibition programs focus on people living with genetic, physical and mental health conditions of all ages and ethno cultural heritages.

POSITIVE EXPOSURE’S innovative approach challenges the stigma associated with difference, and celebrates the richness of genetic diversity. It masterfully combines an appreciation of both Science and Art to explore society’s concepts of beauty and stigma that are associated with genetic physical or behavioral difference cross culturally.

The organization is committed to fostering an understanding of the impact of living with an isolating difference on individuals, families and communities.

***“Your photographs are stunning and the stories behind them are powerful. You conveyed profound messages about stigmatization, self-acceptance, and the impact of a genetic condition on people’s lives. The enthusiasm you bring to POSITIVE EXPOSURE is infectious and the testimonials from the individuals you have worked with speak volumes about the affirmative impact you are having on people’s lives.”***

- Francis S. Collins, MD, PhD, Director, National Human Genome Research Institute,  
National Institutes of Health

POSITIVE EXPOSURE premiered at the People’s Genome Celebration, June 2001, at the Smithsonian’s National Museum of Natural History in DC. and continues to exhibit in galleries, museums and public arenas internationally.

POSITIVE EXPOSURE illustrates how confronting discrimination with powerful images and affirmative stories fights ignorance, how education breaks down fears, how nurturing the individual and community brings celebration and self-esteem, how reinforcing self-esteem produces global change.

The photography and videography process of POSITIVE EXPOSURE offers a fresh exploration of the joy that comes with self-acceptance, providing a look at how an individual's self-perception can be altered by having his or her own image reflected through a positive and life-affirming lens.

Utilizing photography and video interviews, the program investigates the social and psychological experiences of people with genetic conditions of all ages and ethno cultural heritages.

***"I did not see my disease (Alpha One Antitrypsin) in the photos that Rick took of me. I did not see devastation, limitations, or deficiencies. I saw a human being."*** - Kathryn Arnoldi

The results resonate for everyone who has experienced the negative social repercussions of an unconventional physical appearance or has been forced to hide all or part of his or her identity for fear of public ridicule and judgment.

POSITIVE EXPOSURE is committed to include diverse cultural perspectives across gender, age, race, ethnicity and nationality. Hundreds of individuals have been involved in this project to date, their personal stories documented and their powerful images captured on film. The program provides the opportunity for children and adults with genetic conditions, often for the first time, to define themselves by their strengths rather than their condition and disease, and to share advice, building an international community.



KATHRYN, USA 2001  
Writer

"I did not see my disease in the photos that Rick took of me. I did not see devastation, limitations, or deficiencies. I saw a human being." Kathryn has Alpha-1-antitrypsin deficiency, a genetic disorder that predisposes to early onset emphysema, liver cirrhosis and panniculitis, a skin condition.



KAELIN, USA 2001  
Student

Kaelin was 13 when this portrait was taken. Currently she is a junior in high school and is a fan of Nick Lachey, formerly of 98 Degrees. She is on the honor roll, the choir council, the hall decorating committee, the prom committee and the school newspaper. She is excited about her college options. She has Sturge-Weber, characterized by vascular malformations of the skin, eye and central nervous system.



ISABELLE, Cameroon,  
West Africa, 2004  
Teacher

Isabelle, despite the discrimination she faces, has committed her life to the improvement of the social situation of people with albinism. In West Africa, misconceptions about albinism abound, including a rumor that for the national elections to go well, a person with albinism should be sacrificed. Albinism is a genetic condition that results in the reduction or absence of pigmentation in the eyes, hair and skin.



JAMES, USA 2001  
Student

James was 3 when this portrait was taken. He is curious, motivated, determined and mischievous. Currently he is the Mayor of his school, his favorite movie is Wiggles and cars fascinate him. He has Lowe Syndrome, a condition affecting males that causes kidney, eye and cognitive problems.

**POSITIVE EXPOSURE provides the opportunity for people living with difference and audiences alike to celebrate diversity, challenge stigma and embrace each individual's extraordinary uniqueness.**

## Positive Exposure aims to achieve the following Objectives.

- Create the opportunity for individuals, communities and audiences globally to celebrate their uniqueness, individuality, and diversity.
- Raise awareness and increase understanding globally of genetic conditions and diseases and the value of the visual differences between people that they create.
- Create the environment in which our shared vision of touching lives, improving life and embracing the richness of diversity can be achieved by exploring cultural perceptions of beauty and difference across the world.

Students at the Siloe School for the Blind in Polokwane, South Africa,



Positive Exposure has developed collaborative initiatives in:

**United States, Canada, United Kingdom, France, Italy, Mali, Cameroon, Kenya, South Africa, Asia, French Polynesia, Fiji, Samoa, New Zealand, Australia, Panama**

Our organization has a particular focus on albinism, a genetic condition that results in the absence of pigmentation in the eyes, hair and skin. As the heart of our mission, albinism is the metaphorical lens through which to explore social attitudes and behavior toward all difference.

EXHIBITION



To illustrate the universal applicability of POSITIVE EXPOSURE, the exhibition integrates a variety of genetic conditions. It creates a window into the lives of people living with genetic conditions and diseases. Images are exhibited accompanied by informative captions and text.

Visitors to this multi media exhibit are invited to experience the joy of self acceptance vibrating from the photographic images, inspired by the personal video accounts of living with genetic, physical or behavioral differences in society today, enriching their lives through the discovery of seeing themselves in new and different ways.

Noah, NYC, 2005

## The programs of Positive Exposure include:

- Portable and sustainable educational and human rights programs and multi media exhibitions for physicians, nurses, genetic counselors, health care professionals-in-training, elementary and secondary schools, legislators and the broader public.
- Self-Esteem, Self-Awareness, Body Image and Self Advocacy photographic and interview workshops in collaboration with people living with genetic, physical and mental health conditions.



Mere and Family, Fiji 1999

## Positive Exposure introduces an alternative:

- An image database as an alternative to the demoralizing images of people living with genetic conditions currently used in the medical field and in public forums.



Rob, Marfan syndrome USA



Keke, India



Harry, Puerto Rico

Pranish, India



GALLERY



Matilde, South Africa

Ceara, New Zealand



Joseph, Fiji





Gladismira, Kuna

Lauren, Australia

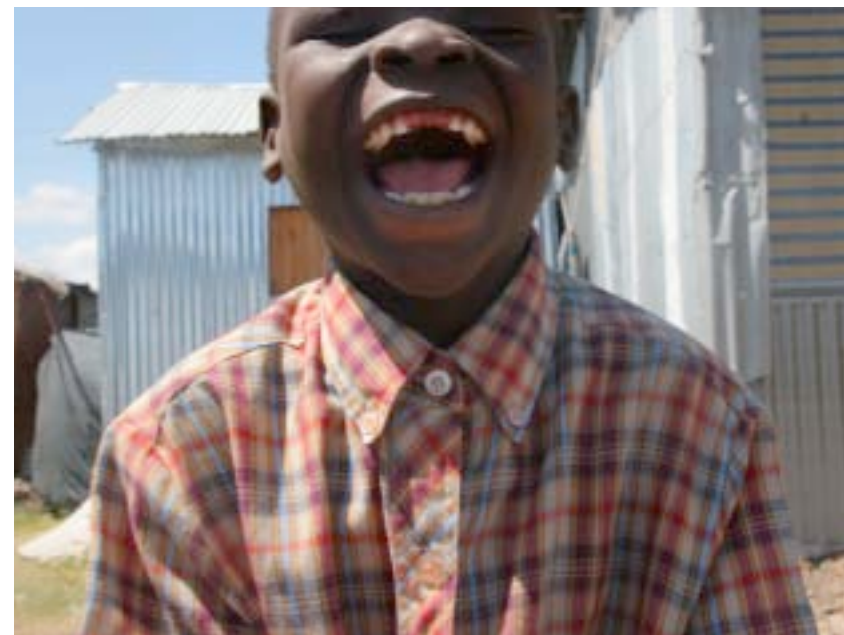


Roz, Australia



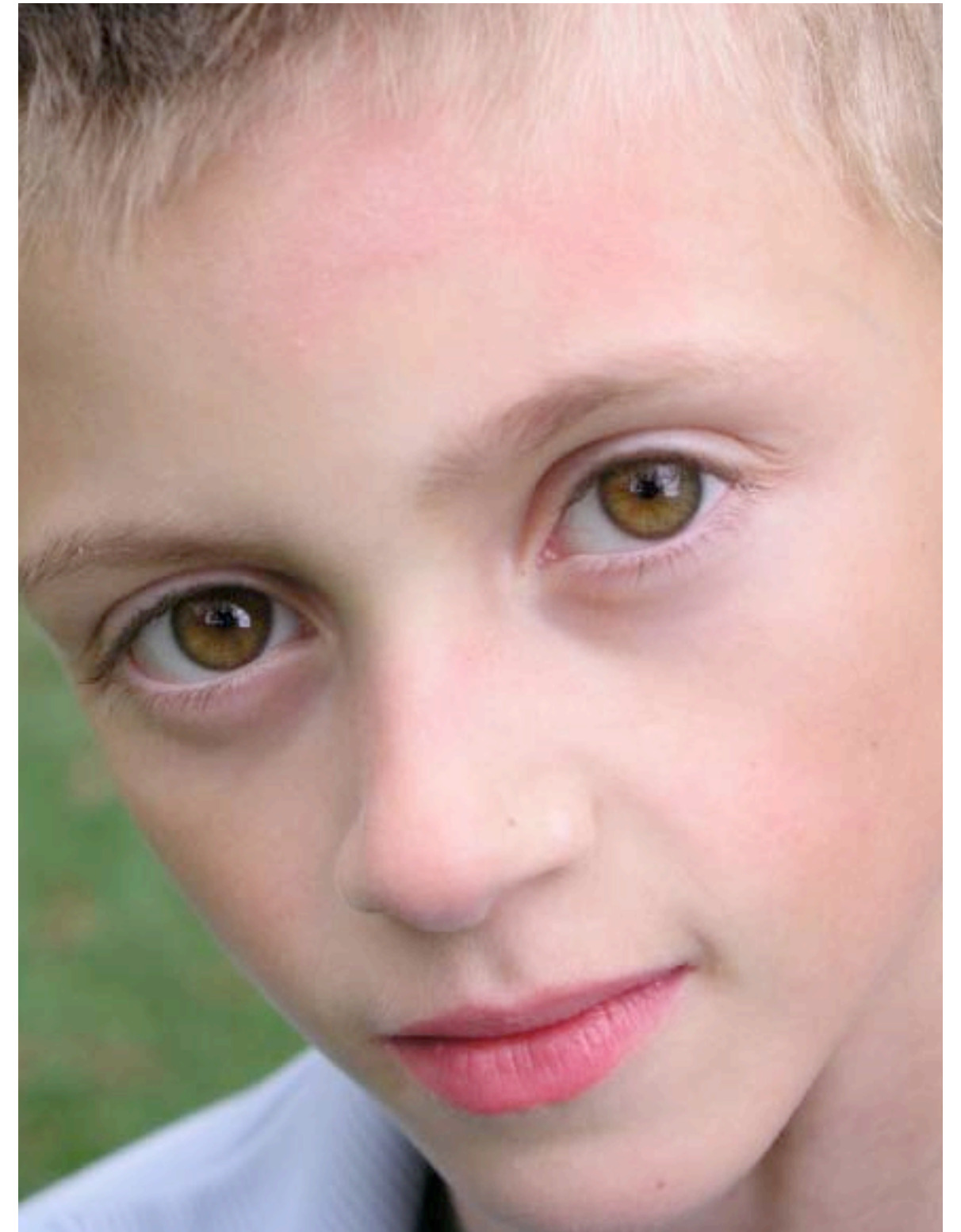
Shayne, IsoDicentric Chromosome 15, USA

Celebrating the  
beauty and richness  
of human diversity



Solo, Hereditary Blindness, Kenya

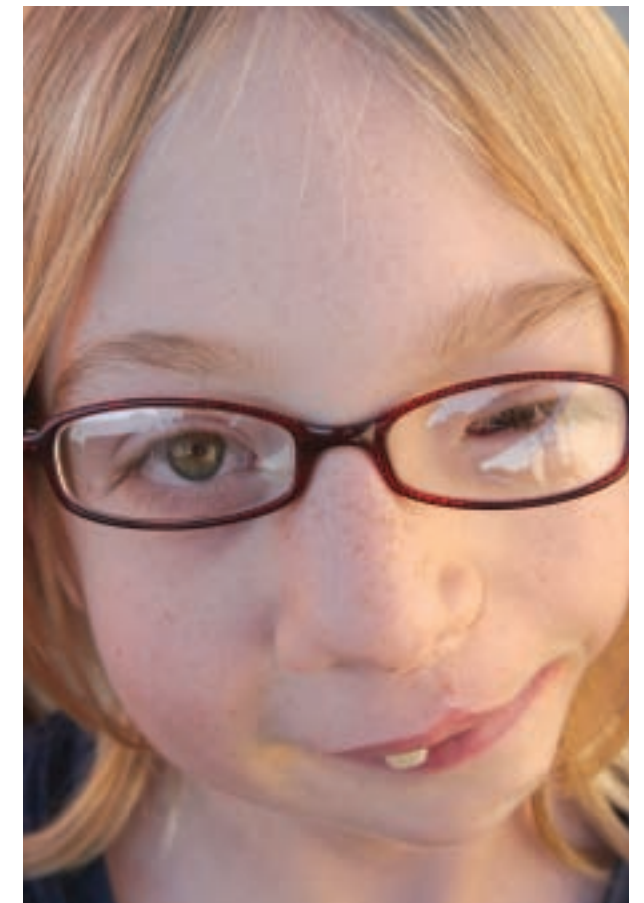
Jordan, Proteus Syndrome, UK





Tammy, Sturge-Weber Syndrome, 2006

Pauline, Chromosome 18 Deletion, 2006



Jayda, 22q11.2 Deletion Syndrome, 2006

**Exhibitions:**

03-04/2008 University of Texas Science Center at San Antonio, TX  
 10-11/ 2007 Texas Children's Hospital, Houston, TX  
 10/ 2007 American Society of Human Genetics, San Diego, CA  
 07/ 2007 Genetic Alliance 25 Year Gala, DC  
 07-09/ 2006 Kuala Lumpur World Trade Center, Malaysia, ICEVI conference  
 10-11/2005 University of Puget Sound, WA  
 08-10/ 2005 Yale University  
 03-05/ 2005 University of Michigan,  
 07-09/ 2005 San Antonio Public Library  
 02-05/ 2004 Condeç Nast Lobby Gallery, New York City  
 04 /2003 Hotel de Ville, Yaounde, Cameroon  
 03/ 2003 Royal Palace, Bamako, Mali  
 01/ 2003 National Marfan Foundation, NY Permanent Installation  
 06/ 2001 Peoples Genome Celebration,  
 Smithsonian's Museum of Natural History, DC  
 03-06/ 2000 Carla Sozzani Gallery, Milan, Italy

**Lectures:**

2008 University of Texas Science Center at San Antonio, TX  
 2007 UNICEF, A World Fit for Children, United Nations, NYC  
 2007 Baylor Institute of Medicine, Houston, TX  
 2007 University of Maryland Medical School. Baltimore, MD  
 2007 Wootton High School, VA  
 2007 American Society of Human Genetics, San Diego, CA  
 2007 National Society of Genetic Counselors, Kansas City, MO  
 1999-2006 Weill Medical College, Medical Students, NY  
 1999-2006 Genetic Alliance, DC  
 2002-2006 NIH, John Hopkins, Genetic Counseling Students  
 2003-2006 American Society of Human Genetics  
 2003-2006 Perkins School for the Blind, MA  
 2003-2006 Ursuline School for Girls  
 2006 Harvard Medical School, MA  
 2006 Childrens Hospital, MA  
 2006 Marshfield Clinic, Practical Genetics for Heath Care Providers  
 2006 University of Indianapolis, Nurse Scholars Day  
 2006 NYU 1st and 2nd Year Medical Students, 2006  
 2006 Harvard, Voices for Africa Graduate School of Education, MA  
 2006 Kenyatta University, Nairobi, Kenya  
 2006 MTV Diversity Program  
 2000-2005 Sarah Lawrence College, Genetic Counseling Students  
 2003-2005 University of Venda and Tshilidzini Hospital, South Africa  
 2003-2005 Siloe and Sibonile School for the Blind, Polokwane and  
 Johannesburg, South Africa  
 2004-2005 American Psychological Association, DC  
 2004-2005 Temple University, School of Nursing, PA, 2004-2005  
 2004-2005 Teachers Roundtable Jarrettsville, MD  
 2004-2005 Yale Graduate Nursing Students, CT  
 2004-2005 National Society of Genetic Counselors  
 2004-2005 Medicine and Pediatric Grand Rounds. University of Texas  
 Medical Center

2005 University of Michigan, Schools of Nursing, Journalism, Art, MI  
 2005 Washington State Dept of Health, WA  
 2005 Scottish National Portrait Gallery, Edinburgh, Scotland  
 2005 World Congress on Chromosomal Research, TX  
 2005 University of Pennsylvania, Health Care Nurse Practitioners and Midwives  
 2005 National Society of Science GA  
 2005 University of Cape Town, Department of Human Genetics, South Africa  
 2002-2004 Duke University: Genetics Interdisciplinary Faculty Training Program, GIFT  
 2004 Children's Medical Center, Grand Rounds, CT  
 2004 Planned Parenthood: Nurse Practitioners, PA  
 2004 University of the Incarnate Word, TX  
 2002 Johnson and Johnson, Ortho-McNeil, NJ

**Annual Workshops, Collaborations and Initiatives:**

1998-2006 Alpha One Network  
 Basil Cell Carcinoma Nevus Syndrome, BCCNS  
 Cardio-Facio Cutaneous Syndrome  
 Chromosome 18 Group, USA and Australia  
 Costello Syndrome Group  
 Forward Face (Cranial Facial Anomalies)  
 Hermansky-Pudlak Syndrome Network Huntington's Disease  
 Iso-Dicentric Chromosome 15, IDEAS  
 Joubert Syndrome Network  
 Little People of America  
 Lowe Syndrome  
 Mannosidosis Group  
 Marfan Foundation  
 MTV, Diversity Program  
 National Organization for Albinism and Hypopigmentation  
 Neurofibromatosis Inc  
 Noonan Syndrome  
 Prader-Willi Syndrome Association  
 PKU Network  
 Proteus Syndrome  
 PXE International  
 Sickle Cell Anemia Society  
 Smith-Magenis Syndrome, PRISMS  
 Sturge-Weber Foundation  
 Trisomy 18, 13 and related disorders  
 22 q Deletion Syndrome

**Current Program Study**

2005-2007 PAVE Program, Photographic and Video Experience, NIH  
 Exploration and evaluation of Positive Exposure interventions  
 effects and sustainability on self-esteem and self-perception.  
 2007 Medical Student ONLINE Survey, University of Maryland Medical School.  
 Measuring Positive Exposure Impact on Disease Perceptions