



## **FOR IMMEDIATE RELEASE**

### **1<sup>st</sup> Annual EveryLife Art Contest Winners Announced** *Foundation Launches Online Rare Disease Art Gallery*

**March 31, 2010 (Novato, Calif)** — On February 28, 2010, in honor of World Rare Disease Day, the Kakkis EveryLife Foundation announced the winners of its first “EveryLife Art Contest.” The purpose of the contest was to empower artists affected by rare diseases to express their unique struggle with the disease and to increase the visibility of the rare disease community.

“We received more than 125 works of art that were not only impressive but inspiring. After reviewing the art, I wanted to create a permanent virtual space where artists could express themselves and allow the public to view these amazing works of art,” said Emil Kakkis M.D., Ph.D., President of the Kakkis EveryLife Foundation.

Inspired by these artists, the Foundation plans to launch [www.rareartist.org](http://www.rareartist.org) to allow artists to upload their artwork and tell their story. Artists will be able to upload multiple works of art and post video clips to tell their stories. All artists who entered the contest will be put in the Gallery, and any artist affected by a rare disease can submit their work.

The EveryLife Art Contest was open to all artists affected by a rare disease age 5 and older. Artists may have a rare or undiagnosed disease or may be close friends, family members, or care takers of those with a rare or undiagnosed disease. A rare disease is one that affects less than 200,000 people in the United States. There are more than 7,000 rare diseases affecting more than 25,000 Americans and their families.

More than 60 artists, young and old from around the world submitted artwork. Each Grand Prize & Special Artistic Merit winner received a Flip Video camera. Winners are encouraged to use the Flip Video to record their story about being an artist affected by a rare disease. The video stories will be posted on the Kakkis EveryLife Foundation website and on the gallery website when it launches this spring. Prize winners also received Visa gift cards ranging from \$25 - \$500.



**The winners are:**

**Grand Prize Winners**

- Children 5-11: Lauren Lachance & Noah P. Thomas  
Teens 12-17: Kassidee Williamsen & Olivia Book  
Adults 18+: Judith Shirreff, Franky Dolan & Lisa Iannello

**Special Artistic Merit**

- Children 5-11: Emma Charney-Sullivan, Ellen Marie Madsen, Tia Piziali & Sarah Elizabeth Brandstater Shaw  
Teens 12-17: Grant J. Bowen, Nathalie Dirnfeld, Hannah Juliette Madsen, Gerald (J.T.) McNeil, III & Lucas Montgomery  
Adults 18+: Jackie Davenport, Holly Lee, Beth Meador, Bithiah Sanchez, Macksi Warner & Tami Weinert

To see their amazing artwork, go to: <http://www.kakkis.org/Contest/>

The Kakkis EveryLife Foundation is dedicated to accelerating biotechnology for rare diseases. The Foundation launched the CURETHEPROCESS campaign to improve the regulatory environment surrounding the Food and Drug Administration's (FDA) approval of effective treatments for rare diseases. The goal is to implement science-driven changes that will increase the predictability of the regulatory process to unlock the potential of existing science and transform it into treatments for these very rare diseases. The Campaign is endorsed by more than 100 patient organizations. Find out more about the foundation at [www.kakkis.org](http://www.kakkis.org) or about the campaign at [www.CURETHEPROCESS.org](http://www.CURETHEPROCESS.org).

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