

**HeartSCAPE: “Creative Arts Pathway to Expression” for Children with Neuromuscular Disorders:
An International Exhibition
By: Petra Kaufmann, MD, MSc**

In March 2009, an International Conference was held in Athens, Greece with the goal to develop guidelines and a forthcoming consensus statement that will inform policy makers, support caregivers, and improve the lives of people living with pediatric neuromuscular disease. The conference focused on Spinal Muscular Atrophy Type 1 (SMA 1) and Duchenne Muscular Dystrophy (DMD), but much of what was discussed would be beneficial to people with other neuromuscular disorders as well. Participants included physicians, psychologists, nurses, social workers, art therapists, and physical therapists with expertise in Neuromuscular Disease, Pediatrics, Rehabilitation Medicine, Pulmonary Medicine and Palliative Care, as well as patient advocates, patients, and parents. Everyone shared the common experience of living with or caring for someone with a neuromuscular disease. The perspectives from each different role fostered a rich and productive discussion. In addition, three continents and seven different countries were represented, which allowed participants to share their specific native approaches to caring for someone with a neuromuscular disease.

The group worked on developing recommendations on how caregivers and members of society can best support people along their journey with neuromuscular disease, starting at the time of diagnosis. Additionally, to raise awareness and ensure that the voice of people living with neuromuscular disease is heard, the meeting included a special evening in a cultural center in Athens. On March 20, 2009, people with neuromuscular disease, conference participants, politicians, ambassadors from several countries, a Greek Bishop, patient advocates, and funding organizations gathered to share their perspective. The event was enriched by a pianist playing a beautiful piece of music he had composed. After the ceremony, the participants visited a very special international exhibit that displayed artwork made by people with neuromuscular disease and their siblings, including children from New York City.

Contributions to the exhibit from the Columbia University Pediatric Neuromuscular Center included the following: Owen, living with SMA 1, created a story and pictures expressing his love of space and dinosaurs; Mercedes, painted a picture of two trees and butterflies flying from one to the other, which she made thinking of her brother who has DMD; Adelina, living with muscular dystrophy, created a lively explosion of colors; and Noah, living with DMD, painted a vibrant heart. All pieces were created at a special event for families that was held at the Children’s Hospital of New York on January 30, 2009. Several family members and children attended the event, as well as several volunteers, and two art therapists from the Child Life and Creative Arts Therapy Department at Mount Sinai who assisted with the event. Children were invited to express themselves through the creation of visual images, poetry, and other creative modalities and some of the resulting artwork was sent to the display in Athens and some of it was kept to be put on display at the Pediatric Neuromuscular Center at Columbia University.

The exhibit displaying the artwork was well received and affected, in some way, everyone in attendance. It certainly raised awareness and exemplified that children and adolescents living with neuromuscular disease have the same interests as everyone else their age – dinosaurs, colors, butterflies, and hearts. The artwork will become part of the permanent art collection of the Muscular Dystrophy Association of Greece, MDA Hellas, a charity organization that raises awareness and funds for neuromuscular diseases.

We thank everyone who made this event possible, namely The New York Life Foundation Wintergarden Programming Series who sponsored, in part, the art event held at Columbia University and the Shuler Family who donated funds for framing the artwork. We also acknowledge the MDA, the SMA Foundation, the Niarchos Foundation and the team from John Hopkins who made this all possible. We especially express heartfelt gratitude to the families and artists for generously contributing their time and work to this special exhibit.

Please see the pictures below which show the artwork on display at the exhibition, accompanied by Dr. Petra Kaufmann and others from the International Task Force, who were in attendance at the event.



Dr. Kaufmann with the artwork from Columbia University Pediatric Neuromuscular Center on display in Greece.

Members of the International Heartsongs Task Force at the exhibition in Greece.
Third from the left: Annie Kennedy, Vice President – Advocacy, MDA.
First on the right: Dr. Petra Kaufmann from Columbia University.

Artwork from Columbia University Pediatric Neuromuscular Center on display at the exhibit in Greece.



Title: "The butterfly like (an) angel of my brother."
Created by: Mercedes, 10 year old sister of Mario (boy age 7 years) with Duchenne Muscular Dystrophy
Inscription: "I always be with my brother and I always take care of my brother. I take care of him more and I could show my love and my heart with him"

Title: "Colors by Addy"
Created by: Adelina, 3 year old girl with Congenital Muscular Dystrophy
Inscription: Question: "What are some things you like about having a sibling with a neuromuscular disorder?"
Answer: from 6 year old brother John: "She is so cute and cuddly."



Title: "Heart"
Created by: Noah, 10 year old boy with Duchenne Muscular Dystrophy
Inscription: Noah had a great time creating art with the help of his parents, nursing students, and art therapists. He used his hands and brushes and sponges to paint.

Title: "My name is Owen..."
Created by: Owen, 6 year old boy with Spinal Muscular Atrophy, Type I
Inscription: Letter with art work.
"My name is Owen and these are some of my favorite things: t-rex, shark, and Saturn (pictures).
Hello my name is Super Owen. I have Spinal Muscular Atrophy but I sometimes move my body. I am six years old. I live in Brooklyn New York. I love science so much. I want to study books on space. I love sharks so much. They can become so strong so fast. I like some dinosaurs – my favorite is t-rex because he is very smart but scary. I am best at writing space tests. You can sometimes sing or write stories about space. Owen Ort Land (picture).