

XXYY Sibling Project Reaching New Audiences

As research assistants in the eXtraordinary Kids Clinic, Children's Hospital Colorado, we helped to manage and organize research data. We also provided support for research patients and our work included frequent interactions with families. Often brothers and sisters accompanied families during appointments to the clinic. Our initial interactions with siblings of boys with XXYY were limited to brief conversations in waiting rooms as their brothers completed visits with Dr. Tartaglia and the rest of the clinic team.

When the idea of a sibling project was first suggested to us we knew we had a lot to learn about growing up with a brother with XXYY. Clinic waiting rooms provided little opportunity to gather the depth and breadth of information we knew would be important for this project, so we started our journey in earnest with cameras and questions in hand. Our first experience was with several families at a small gathering by a quiet mountain lake near Pine, Colorado. Here, simple conversations gave way to complex stories and opened our eyes to the challenges, frustrations, and lessons of acceptance within each family. Armed with new understanding, we continued our discussions with siblings from Boston, South Dakota, San Diego, Los Angeles, and Colorado. We asked a lot of questions but mostly listened and filmed as many siblings shared their insight and wisdom with us. Each sibling added to a narrative about triumph and hardship, compassion and adversity. Ultimately we came to realize siblings were sharing a hopeful view of loving, understanding, and acceptance. It became increasingly apparent that these were voices that needed to be heard. We were convinced these stories could not only inspire siblings, but all members of the XXYY community.

We are not filmmakers. We are both health science majors committed to understanding and contributing to health care. Our first vision for this project was a simple compilation of our interactions with families. Upon beginning this project however, we soon realized the immense challenge of editing such a large collection of video and sound. It was the inspirational stories we heard that drove our efforts. After speaking for hours with those we met on our journey, we decided to focus on the common themes and messages we heard from so many. While we could not include all the people who so generously shared their time with us, their common experiences emerged with clarity. Ultimately, our goal was to give siblings the chance to share their stories, provide guidance to one another, and unite a community of mutual support and understanding.

Dr. Tartaglia first shared this video June, 2017 at the XXYY Project Family Symposium in Colorado Springs, USA. To our excitement the project moved internationally to several showings in August, 2017 at a conference in Derbyshire, United Kingdom. Each audience received the XXYY Sibling Project with great enthusiasm and viewing the video opened new discussions between siblings and parents. Audience members, regardless of their experience with XXYY, were able to connect to one another in a different way than before.

The XXYY Sibling Project does not stop with this video. We hope to inspire conversation beyond this documentary, as it is the discussions and reflections of audience members that make this project so powerful.

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