

Kylie's Healing Bedroom Makeover

ABOUT KYLIE

Kylie is a 15-year-old who lives with her parents and older brother in Spencer, NY. Kylie was born with Titin (TTN) Syndrome, a variant in the Titin gene, which affects the muscles in her body from functioning properly. She has seen many specialists, but the related muscle and heart disorders she has are still being explored and determined. Her condition has worsened as she's grown, and she must use a wheelchair daily.

HOME VISIT

ARTH identified Kylie as a candidate who could benefit emotionally and physically from a healing environment in her bedroom. Kylie has been sleeping in her parents' bedroom, feeling comfortable having them close by. Her room was not functional: there was limited room to navigate through the space, she could not reach things in her closet, and there was no place for friends to sit and visit.

OBJECTIVE

The goal of this project is to create an environment that takes Kylie's medical needs into account, while also allowing her warm and bubbly personality and various interests to shine through. The team wants to transform Kylie's bedroom into a safe place where she feels comfortable and independent so she will start sleeping in her own space. She will be able to reach her clothing, open her drawers, and use all of the elements included in the new space even if she continues to lose muscle function.



AT A GLANCE

Needs

- Adjustable bed and transfer board
- Storage she can reach and open
- New carpet
- A way to contact mom from her room
- A place to hang out with friends

Challenges

- Carpet must hold up to wheelchair use
- Space is small
- Kylie's physical limitations
- Budget: \$6000

BEFORE IMAGES



SOLUTION

- Using Kylie's interests as inspiration, a design board was created with beautiful colors, textures, and décor.
- An adjustable bed/mattress was provided that is the same height as her wheelchair. A transfer board helps to ease the transition from wheelchair to bed.
- An Alexa system with a doorbell located next to her bed gives her a reliable way to communicate with her parents and eases her fears of being alone in her room.
- LED lighting was installed that is controlled by smart technology
- In the closet, a lower rod and motion light were installed. Curtains make it easy to access the closet and can be closed to hide everything.
- A new dresser was fitted with pulls that are easier to use than a knob
- A door was added to the room for privacy
- We provide her with the requested make-up and jewelry vanity, perfect for a teenage girl.
- A comfy bean bag chair gives her friends a place to sit
- A low-pile commercial-grade carpet is easy to navigate in a wheelchair or with a walker and will stand up to the tires of the wheelchair.

DURING



RESULTS

The finished design is not only aesthetically beautiful, but it also addresses all of Kylie's needs. It allows her to be much more independent and is a place she enjoys being now.

Kylie's Dad sent a message to the project team: "Thank you all so much again. She has been loving her new room. Sleeping in her new bed, and being in her space at home has made her so happy. We appreciate all the hard work from you and your volunteers."

The project team was successful in meeting all of its goals and creating a space where Kylie feels safe and comfortable.

AFTER IMAGES



ACKNOWLEDGEMENTS

Linda Salomons for leading the project, Angela Grasso for the beautiful design, and all of the volunteers who gave their time to this project. Alert Alarms for transporting the furniture and items to Kylie's home. LaRosa Carpet for their donation of the carpet and installation. Floyd Hooker Foundation for their generous grant.