



Bekah and her husband Danny and their two boys Titus and Ely (pronounced Eli), entered the Batten world in 2015 when both boys were diagnosed with CLN2. In the past seven years, they journeyed two very different roads with their boys. Titus passed away in September of 2016 at the age of six from an aggressive decline from the disease. Their son Ely entered the compassionate use leg of the Brineura trial at three years old.

Bekah has taken her experience as a rare disease mom and used it to help others who find themselves on a grief-filled journey. Through her blog, and eventually, her book *Can't Steal My Joy*, she has been honored and humbled to journey alongside others as they experience grief and hope together.

Bekah is the Executive Director of CASA of Southwest Idaho, a nonprofit that advocates for 600-700 abused and neglected children in their community each year. She is passionate about advocacy for those who cannot speak for themselves, and this passion certainly was sparked on the day Batten was spoken into her family.

Bekah loves being Titus and Ely's mom, wife to her best friend Danny who coaches track and field at the collegiate level, and friends with so many incredible people she's been blessed to meet along the way in this adventure called life.



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