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On the Cover
Ella’s mother writes: “Ella is two years old and has an extremely rare brain disorder called Congenital Bilateral Perisylvian Syndrome. Ella’s brain never fully developed nor did the outer covering of her brain or the motor cortex. Because the motor cortex never fully developed, Ella isn’t able to swallow or eat by mouth, and because the outer covering didn’t fully develop and her brain is immature, signals from the brain to certain body organs don’t work. Her brain doesn’t send the signal to her intestines, so Ella has a form of intestinal failure called Intestinal neuropathy/brain gut dysfunction. She is unable to eat, and is 100% TPN dependent (IV nutrition), which she receives through the central line in her chest. The line you see in her chest sits in the main vein of her heart, and that’s how she receives all her nutrition. There is a 75% chance that children with this brain disorder have some form of mental retardation as well as epilepsy, hearing loss, and blindness in childhood. Ella is also hypoglycemic; she has an atrial septal defect (ASD) (hole in her heart) that will be fixed soon. In addition to pulmonary valve stenosis (another heart defect), Ella also has airway disease. She has been through a lot, but she proves how strong she is everyday. She is absolutely amazing, and we cherish every moment we get to spend with her!”

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