

HICCUP

HICCUP  
FIRST EDITION

THE NEW YORK PUBLIC LIBRARY  
ASTOR LENOX TILDEN FOUNDATION  
155 E. 42ND STREET, NEW YORK, N.Y. 10017

In the summer of 2019, I was sent a text message by my girlfriend's mother asking if I could stay a little longer at the climbing wall as they needed to have a chat with their daughters. A few hours later when I arrived home I was told by Poppy, my girlfriend, that her mother and grandmother have Huntington's Disease. She then told me that there was a fifty percent chance that she, her sister and cousin could have it too. As her boyfriend, partner and best friend this was something that shocked me. One day in the years to come, if Poppy tests positive then I will take on a palliative care role. I will have to watch as her condition deteriorates, and life becomes more complicated. No one wishes that upon someone they love, and I do not wish to see it happen.

Hiccup documents the life of a family dealing with Huntington's Disease, a hereditary illness that affects the central nervous system causing parts of the brain to become damaged over time. The project primarily focuses on Pamela, Earnie and Poppy; grandmother, mother and daughter. Pamela is in her 70's experiencing physical and mental symptoms. She was diagnosed in October 2017. Earnie, in her late 40's has had a positive diagnosis and found out in April 2018. She managed to keep the diagnosis of her mother and herself a secret until they were ready to tell the rest of the family. Poppy, now 21 is currently studying illustration at university and must attend genetic counselling to find out whether or not she has the condition. She is yet to start the process. I would also like to mention Poppy's sister Libby and cousin Bethan whom, like Poppy both have a fifty percent chance of having Huntington's Disease.

Over the course of a year I have documented their lives and observed the ways in which they live in the shadow of Huntington's Disease. My close connection to the family has allowed me to observe and capture intimate moments in all of their lives. Rather than focusing on the disease I've tried to capture the love and connection shared between this family, one perhaps unlike any other family I know. Honesty, love and compassion are the foundations of their relationship and I hope you can see that in these images just as I do.

FOR THE KIRK FAMILY

The title 'Hiccup' was inspired by a medical term that refers to an interruption of the HD chain resulting in a hiccup thought to slow down the onset of the disease.





























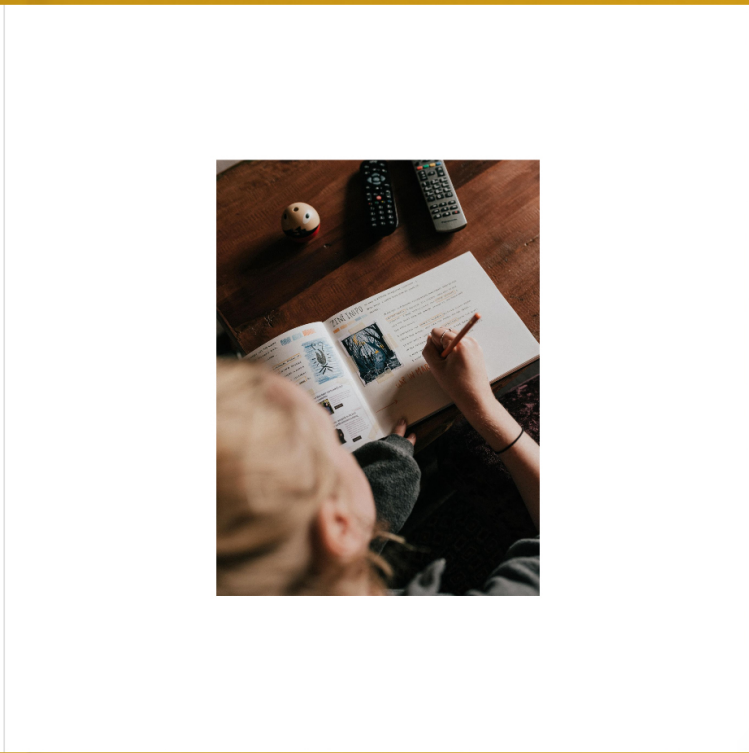
































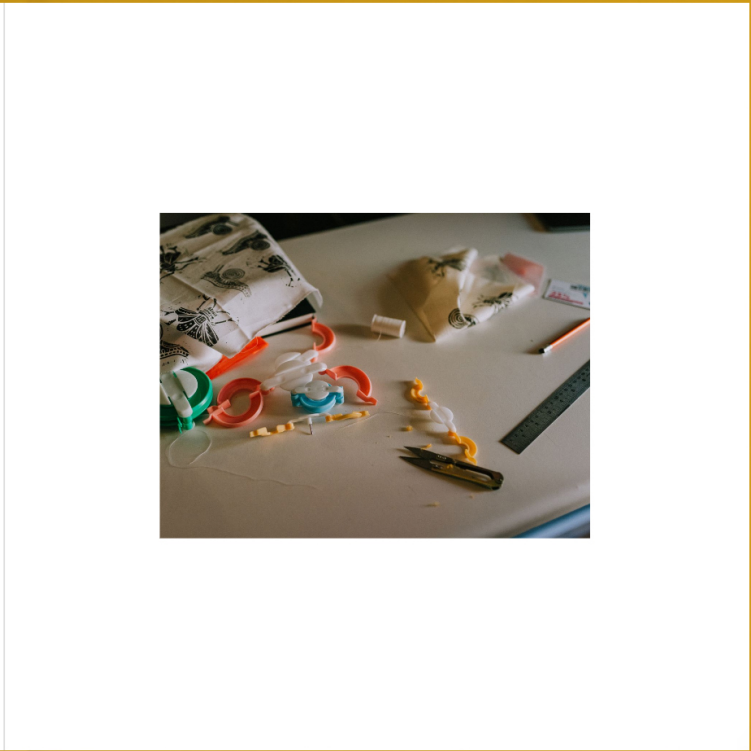


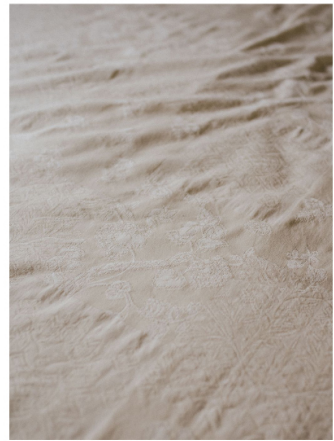














#### Acknowledgments

Thank you to Pamela and Alan Bushella for allowing me into their home to document their lives and making me feel comfortable from the very start.

Thank you to Earnie, Poppy, Andrew and Libby Kirk for always being honest, caring and putting up with the constant clicking of a camera.

Thank you to my mum and dad who have supported me through, school, college and university even though I was constantly pessimistic. Here is something to be proud of.

Thank you all.