

Chromosome 18 Conference - Charleston, North Carolina - July 2024

Slide #1: Schedule for the conference

Slide #2: Enrollment numbers for the C18 Study (The research arm of the C18 group) Lillian is in the p- group. With being a part of this study, in 2012 Lillian and I both gave blood samples to the C18 Research arm so that we could be included in findings that they periodically release. We also complete surveys and smaller studies to receive findings.

Slide #3: We are world wide

Slide #4: Breakdown of the amount of genes in Chromosome 18 (Again, Lillian is p- ... missing the short arm of #18)

Slide #5: Molecular genetics of chromosome 18 deletions

Slide #6, #7, #8 & #9: Findings regarding studies

Slide #10, #11, #12, & #13: Findings of an 18p- survey

Slide #14: Resource available for members

Slide #15: Information regarding blood draws. This is how you become a part of the studies.

Slide #16: Group photo of 18p- (self-advocates and family members) not everyone is included. As you can imagine it's quite hectic trying to get group photos. Lillian missed this. Thomas and I are in it.

Slide #17: Group photo of everyone (some are missing)

Slide #18: Group photo of all self-advocates (some are missing)

Slide #19: Macy (18p-), Camilla, Lillian (18p-), Lauren (18p-) and Kelcie (18p-) - Macy, Lillian, and Lauren are all the same age, 22 years old. They met through the conference about 10 years ago and are really good friends. Kelcie is a newer member. She and her family joined a few years ago. I think she is 28 years old.

Slide #20 and #21: Macy, Lauren and Lillian

Slide #22: Camilla, Mary and Jonah (18p-)

Slide #23: Thomas (Lillian's younger sibling) and Isaac (not sure which 18 syndrome he has). Thomas and Isaac met at the 2016 conference and adore one another

Slide #24: Camilla and some of the moms with some of the older siblings, goofing around

Slide #25: New this year - A closed parent panel for siblings only. I represented single parents. Those who had the role of mom and dad. Siblings asked questions of us.

Slide #26: Sibling Panel - Thomas is 4th from the right. No self-advocates allowed as parents are asking questions of the sibs. This allows the sibs to comfortably and honestly answer the questions.

Slide #27: Sibs on Sibs night out - Local Amusement Park - Thomas is front and center, kneeling

Slide #28: Moms Night Out - Not everyone

Slide #29: Self-Advocate Night - A Luau - Kelcie, Macy, Lauren, and Lillian