



Lara Bailey

From: Chapel Hill, NC

Age: 33

Carrier Status: Mosaic

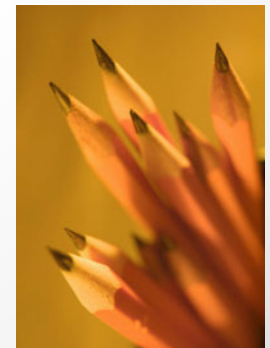
Diagnosed at age 8

Too young to really
understand what FXS was



Grade School Days

- Attended public elementary, middle, and high schools
- Started seeing a resource teacher in 4th grade
- Middle school was hard
- Went to a private school a half a day in 9th grade
- Had tutors all throughout school mostly for math
- Mostly good teachers
- Algebra teacher in 11th grade who was unhelpful
- Awesome Chemistry teacher in 11th grade who provided tutoring and review sessions every Thursday
- Graduated from Chapel Hill High School in 1996



College

- Started at Appalachian State University in Fall of 1996
- Lived on campus, great roommates
- Majored in Graphic Arts and Imaging Technology with a minor in music
- Had one really awful professor (physics)
- Involved in band, joined a fraternity
- Graduated in 2000



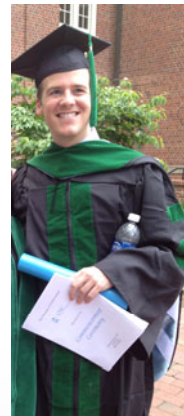
Work

- Currently work at the School of Information and Library Science at UNC-Chapel Hill
- Responsible for 350 Graduate students
- Have wonderful and supportive coworkers
- Learning computer skills such as web page editing, and word processing like excel and ms word.
- Had some bad supervisors in the past



Advice

- Support the NFXF
- Attend the conference
- Get involved in your state or country's fragile x group
- Surround yourself with supportive friends and family
- Become your own advocate



Females with Fragile X Panel 2012

My name is Allison Gayle
Cohen.

I am 23 years old.

I live in West Bloomfield,
Michigan.



Vital Statistics



- Carrier status: Full mutation, 200 + repeats, high functioning
- Age when diagnosed: 5 years old
- How I felt when diagnosed: I didn't learn until I was 8 years old that I had fragile X. I felt relieved because I finally found out why it took me longer to read and understand.

Recent Activities



- Last March I attended NFXF Advocacy Day. This was the third time I attended. It was a great experience and I felt like I made a difference in the fragile x community.

Oakland Community College

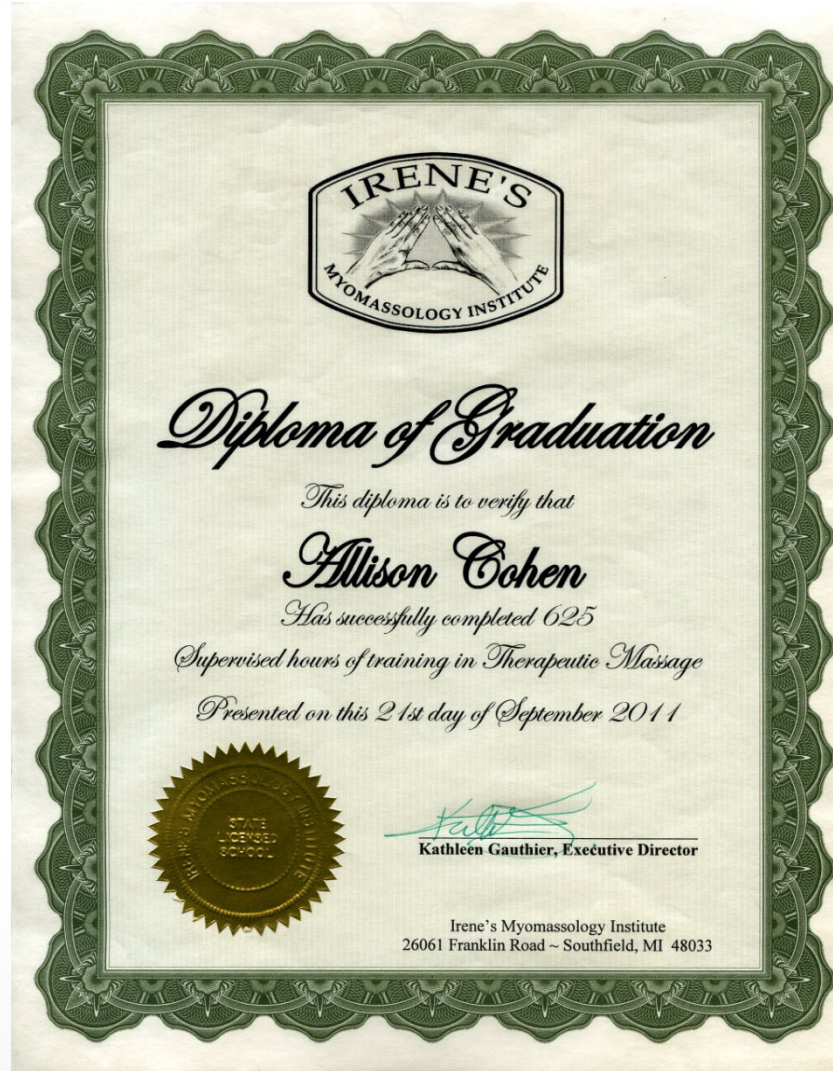
After graduating High School I attended Oakland Community College for 3 years. I felt like I didn't have any idea of what I wanted to do. I liked to work with my hands and thought of massage school. As luck would have it there was a nationally known school right near where I live. So I looked into it and liked what I saw.

Irene's Myomassology Institute



I took classes in pathology, anatomy, and physiology. I knew that I had to learn about the body I just didn't know how much I had to learn until I got all the books for my classes.

My Diploma



School Issues

I graduated from Irene's in September 2011 with perfect attendance. I received help with all my tests from my amazing teachers. The accommodations I received were extra time on the tests, a reader who read the test questions to me and a separate room to take tests in.

Work Experience

- After I graduated from Irene's I got a job at a Spa near my house. The most massages I would do in a day was 10 (that's a lot). But the spa and my boss were very disorganized and I never knew what my schedule was. That was very hard for me so I quit.

Healing through Massage



I have now opened my own private in-home massage service. The name of my business is ***Healing Through Massage***. I go to the homes of clients to give them massages.

Organized

- To help me stay organized I schedule all my massage appointments on my iphone and my google calendar. When I have a massage coming up my iphone will remind me so I don't forget. I also have a check book app on my iphone so I can keep track of money that I earn and spend.

Interview Process

- I've also been interviewing at different spas. What helps me get ready for my interviews is that I write down all of the questions I want to ask on a separate sheet of paper. I also bring a note book to write down anything I need to remember that comes up during the interview.

Healing through Massage



My most popular massages are deep tissue and hot stone massages

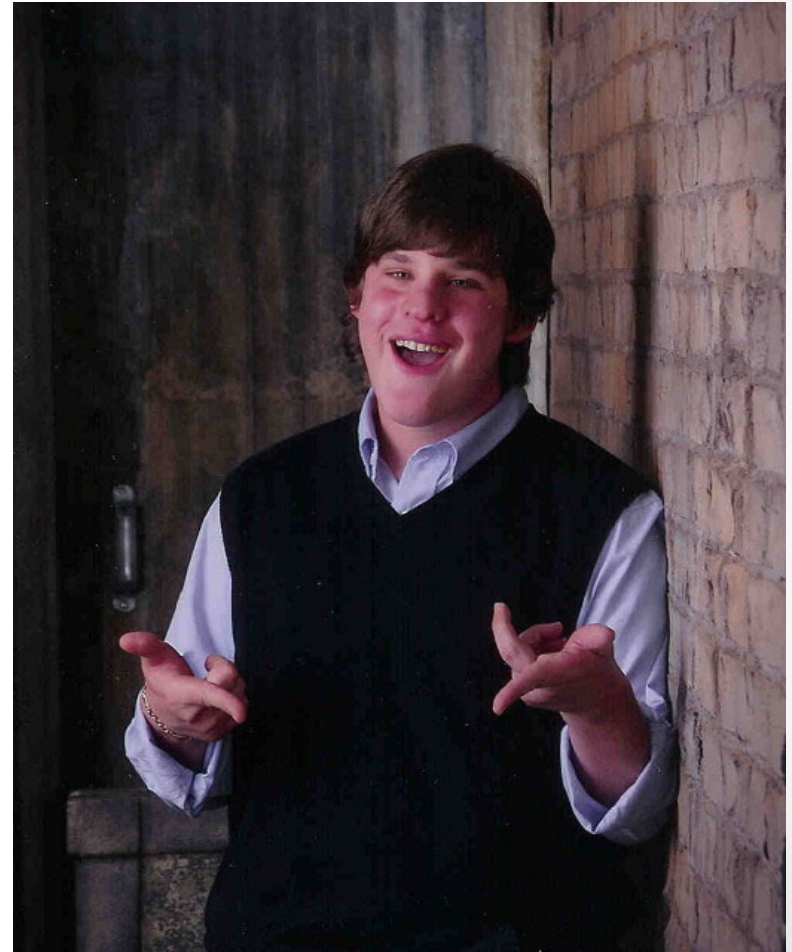
For each appointment I bring my massage table, sheets, music, oil and lotion, and candles.

My Future Plans

The great thing about working is that I can make my own schedule and keep track of important things I have going on. I am saving my money so that one day I can move out and support myself. Hopefully by the conference in 2014 I will be living on my own.

My brother

My brother is one of the coolest people you will ever meet and even though he can annoy me and drive me crazy I still love him very much.



My brother Josh

- The thing about my brother is that often I feel like I have to take responsibility for him. My parents always tell me not to worry about Josh and to let them handle it. I know that I don't need to worry about my brother but I cant help it sometimes.

How I feel about having Fragile X

- Having fragile X is something that I am proud of because learning to cope has made me a better person. I have caring and supportive people in my life that I can ask questions about FX.
- If there is a cure for FX I wouldn't take it because I am happy with myself the way I am and I wouldn't want to change anything about me for anything in the world.

My message to you

- FX has been a challenge and a blessing. A challenge because it can be frustrating not being able to figure things out for myself but a blessing because I have learned that it's ok to ask for extra help. I have lots of support from family and friends.
- **If there is one thing I would tell others with FX** its that its okay to be scared the first time your parents tell you that you have FX but its also ok to ask questions. At 8 I didn't really understand, but now I know that fragile x is a part of me and I'm good with that.

My message to you

- **If there is one thing I would tell parents** it is to be honest with your kids and don't keep FX from them for a long time. My parents were always honest with me from the beginning and it helped me become stronger.
- **If there is one thing I would tell teachers** it is to be patient and don't get mad when your students don't know the answer to a question. Be understanding and listen when they ask for help on an assignment or a math problem.

Anna Cohen

- 23 years old
- Studied Bachelor of Early Childhood education at University of Melbourne - 4 years
- Currently studying
- Post-Graduate Masters in Special Education p/t
- Work part time as a kindergarten teacher and also at gym creche



Anna Cohen

- Drivers license in 2008
- Spend my spare time hanging out with friends going out to bars and restaurants, going to gym or listening to music.



Anna Cohen

- Older brother Michael diagnosed age 8 years
- I was 6 yrs when diagnosed - not told till I was 9



Anna Cohen – Impact of FXS

- Lot of difficulty with math in school. Good at other subjects such as psychology and other humanities subjects.
- Organizational problems
- Anxiety - on medication
- Bullied in junior high co-ed school
- Moved to all girls middle to senior school - much better

Anna Cohen - Experience with FXS

- Difficulty accepting myself for who I was
- Did not tell friends until senior year I had FXS
- Now I have accepted myself- took a very long time
- Friends have accepted me as well
- I hope to use my experience with FXS to work with children with special needs and become a special education teacher

Fragile X and Me

By Bethany Collins

The Basics

- Name: Bethany L. Collins
- Age: 27
- Carrier Status: Full mutation
- Age When Diagnosed: 2 ½
- Siblings: brother- Lee (25) and sister- Kim (31)
- Currently: In school at local community college



The Family



Family and Friends



School Issues

- Math – tutoring and special classes
- Writing – I wrote my N's, C's backwards
- Had OT and speech therapy (couldn't pronounce my R's) at school till 4th grade
- Teasing
- Problems paying attention and staying focused
- Slow at completing work



Work Issues

- Slower when counting money
- Trouble dealing with boss
- Difficulty getting there



Impact on My Life

- Driving

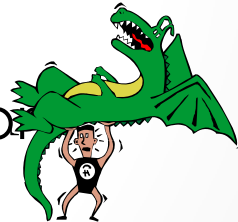


- Depression

- Making friends



- Strengthened my determination



- Understand people who are different



Words of Wisdom

- Fragile X makes me who I am
- It will get better
- Don't blame yourself
- Don't give up!



Me and The Backstreet Boys



A Dream Come True!

Chelsea Elizabeth Owens

18 years old from Crestview, Ky.



FXS Full mutation

Diagnosed at the age of 7



**FRAGILE X
SYNDROME
BY CHELSEA
OWENS**

May 2009 Term Paper

**Understanding
Fragile X**

Immediate Family

Kaitlyn, Dad (Shane), Me, Mom (Paula) and Thomas



Me and my cat Fluffy



FXS Roots- Heisel Family

Family members affected by FXS



Right - My Uncle
Aaron (Full
Mutation)



Above- Cousin
Larry (Full
Mutation)





SCHOOL

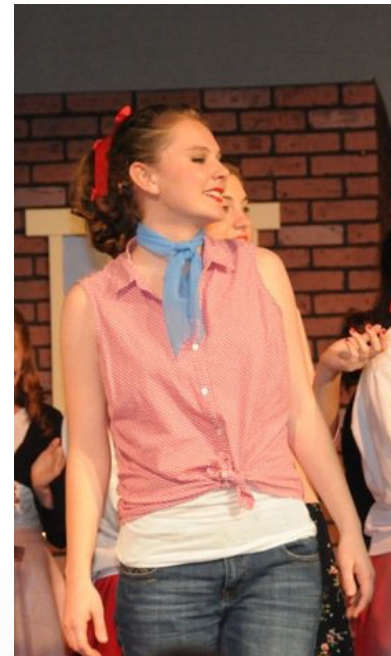
MATH



SHYNESS



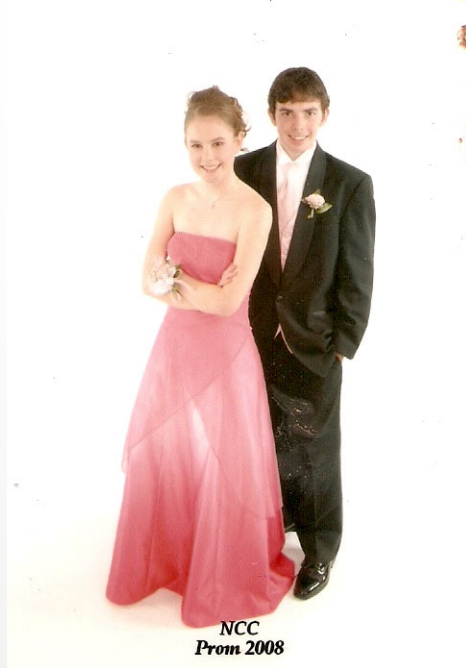
Activities



Friends



What is Chelsea doing now?



Future Plans!

**How FXS
affected my
life...**

Advice from the Vocational Rehab
of Kentucky;

GO TO SCHOOL!



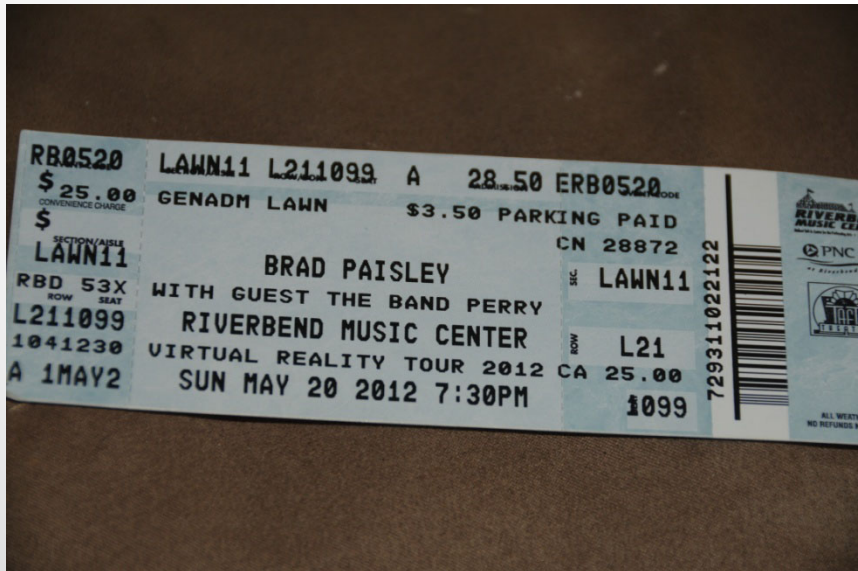
Applying to Gateway
Community College in
Kentucky





Classes and Part Time Work at Aunt Kathy's Daycare Keeps Chelsea Busy

Chelsea Enjoys Spending Time With Her Boyfriend John. They Work on Celebration Retreats Together.



John and Chelsea Also Enjoy Country Music and Going to Concerts. Especially Brad Paisley.

Chelsea Relaxes at Home
Reading and Playing with
Her Cat “Fluffy”.



She Hopes to Get a Full Time
Job in Child Care When She is
Finished with School.