Alexander's Not-So-Secret Diary

Meet Alexander, a pretty cool kid born with a really rare condition.



FOREWORD

Dear reader,

It is my honor to share these words with you.

Ten years ago, my daughter, Fia, and I began our journey with Alexander disease, one we never expected or anticipated. The pages of Alexander's Not-So-Secret Diary share a glimpse into our experience — one story among many in a community shaped by courage, connection and hope.

These pages hold space for the tears, exhaustion and grief that can accompany this journey, while also reflecting the love, laughter, joy and celebrations that make it deeply human. Through Alexander, readers can see the person beyond the disease, his interests, relationships, dreams and personality.

Our hope is that this book can be a resource for anyone who wants to learn more about Alexander disease and a starting point for open, honest dialogue. It can help us listen more closely, ask better questions and recognize experiences that are often unseen.

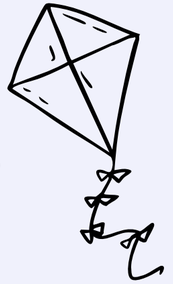
Most importantly, it is a reminder that no condition defines a whole person. Each of us has something special that makes us unique. We are all standing on the shoulders of those who came before us, and their stories continue to help pave the way forward. By sharing stories, building connections and looking ahead together, we can create a future with greater understanding, inclusion and possibility, and offer more knowledge, light and hope to those who follow.

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Mum to Fia, another pretty cool kid
living with Alexander disease

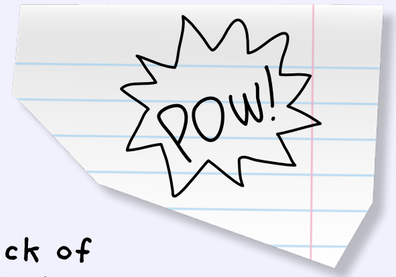


THURSDAY, SEPT. 5



This is it—the first page of my new diary! Not sure where I should begin, so I guess I'll start with the basics:

1. My name is Alexander.
2. I'm 9 years old.
3. I have a pretty cool family. My mom's name is Sandra and my dad's name is Oscar, but everyone calls him Ozzie.
4. Emma's my little sister. She's 6 and just started first grade.
5. My favorite colors are blue and orange.
6. I have a condition called Alexander disease, which is why I use a power wheelchair to get around.
7. I REALLY like video games!



Mom and Dad got this for me to keep track of my thoughts and feelings and stuff like that. I think it'll be fun.

TUESDAY, SEPT. 10

Saturday is going to be a GREAT day!

I've got a friend from school coming over. Her name is Sophia, and she likes to play video games. And she doesn't seem to care about my chair or when my words don't come out the way I want, so that's cool.

I just hope Emma leaves us alone while she's here—little sisters ALWAYS try to butt in!



SUNDAY, SEPT. 15

I had a great time with Sophia yesterday. She laughed at my jokes, and she's pretty funny too. She wanted to know more about my chair, and I told her it's because I have Alexander disease.



TWO THINGS:

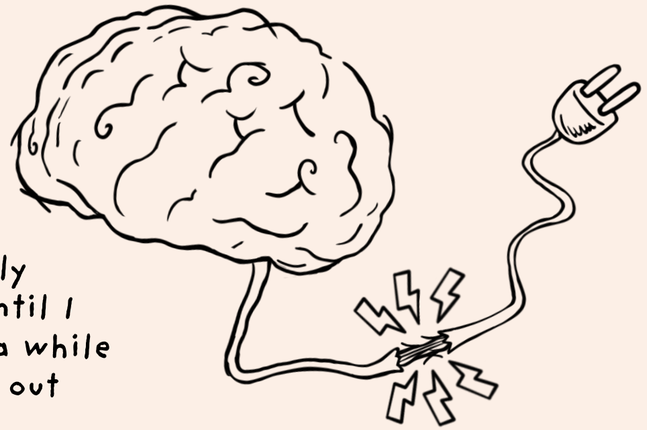
1. Sophia asked if the disease was named after me and I said NO, but it does make it easier to remember!

2. After I explained it some more, she said I should tell our whole class about it at Friday's show-and-tell. That sounds kinda scary, but Sophia says it would be awesome.

FRIDAY, SEPT. 20

I DID IT!!!! I explained Alexander disease to the class today! Mom and Dad helped me figure out what to say.

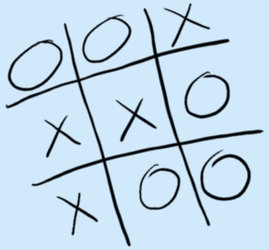
I said it's a condition I was born with where sometimes my brain has problems telling the rest of my body what to do. Dad said to tell them it's sorta like a power cord that's broken, so the electric signal can't get through. They liked that.



I also told them my family didn't notice anything until I was 4, and then it took a while for the doctors to figure out what it was.

Some of the kids who hadn't talked to me before came up and asked me some questions. That made me happy.





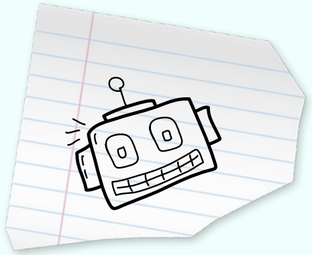
MONDAY, SEPT. 23

We went to the park yesterday. It was good to get outside. There was this giant tic-tac-toe board, and I got to play with some other kids. I won 2 out of 3 games!

I also saw some kids playing soccer. I used to play a couple of years ago, but I can't anymore because my legs do their own thing now. Some days they work, some days they don't. (Mom says it's like having my left foot on my right leg and my right foot on my left leg.)

That's okay. I still had fun, and being able to play tic-tac-toe with the other kids made me feel really good.





WEDNESDAY, OCT. 2

I met another kid with Alexander disease! His name is Jayden, and he lives in Colorado, and our moms set up a video call for us. He's the only other kid I've met who has it too, since it's really rare.



We talked about how Alexander disease never goes away and how things will probably get harder as we get older.



But the GOOD news is we both have lots of help. I go to a lot of different kinds of therapy (like exercises and practice with my speech and stuff) to help me feel my best. And my family and friends, like Sophia, are really awesome.

No matter what, they're ALWAYS there for me, even Emma.

FRIDAY, OCT. 4



Today is a big day. Mom and Dad are showing me how to use my new AAC device.

AAC stands for "augmentative and alternative communication," but I'm just gonna call it "the tablet." I'll be able to use it to tell them things or even make jokes on days when it's hard to use my own real voice.

That's starting to happen more and more, so this will be really helpful when my voice decides to take a break.

SATURDAY, OCT. 12



I got a little sad today.

There's a new movie I REALLY wanted to see, but when Dad called the theater, they said their elevator was broken. The guy on the phone told him it would be fixed in a couple of days.



Dad could tell I was down and said it's okay to feel that way because everyone gets sad once in a while. He said when he gets sad, listening to music helps cheer him up.

I told him reading a comic book or playing a video game with friends usually does it for me.



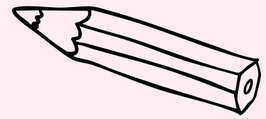


TUESDAY, OCT. 15

Mom asked how things were going with my diary, and I told her I'm really enjoying it. She was SO happy. She said maybe other kids could read it someday so they can understand Alexander disease a little better.

I think that's a good idea.





FRIDAY, OCT. 18



Okay, for anyone reading my "not-so-secret diary," I just wanna say two things to remember above all else...

1. I might seem really different at first, but I'm just like any other kid, except I have Alexander disease. That's something that makes me special. You might have something else that makes you special too!
2. I'm still Alexander, no matter what. I still like video games, funny jokes, watching soccer, and banana smoothies. (And sometimes, I even like hanging out with Emma, but don't tell her that!)

That's all for now. Thanks for reading—and who knows, maybe we'll get a chance to be friends someday!





Nine-year-old Alexander shares a name with his condition, Alexander disease, which makes it easy to remember. From navigating school in his chair to learning how to use a speech device, Alexander faces his challenges with humor and heart. Supported by a loving family and loyal friends, he shares his story with his classmates and reminds us that everyone has something unique that makes them special.



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