



**"No Cross,  
No Crown"**

# The Cross and Crown

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*Editor's Note: As much as possible, I try to avoid having this newsletter become a personal journal about my family and me. At the same time, I know that many who read it have been praying for our daughter, and some have asked for updates. With her permission, I'm sharing a summary that she posted on social media last month.*

Just wanted to give everyone an update of my past year. I have Ehlers-Danlos Syndrome (EDS), a connective tissue disorder, and 10+ other chronic conditions.

A few years ago, I began having "migraines" – intense head pain and neurological symptoms. I tried every treatment imaginable, but nothing helped, and my symptoms continued to worsen.

Last spring, things got really bad as I began to have episodes where I literally couldn't hold up my head or legs, was having daily black out spells, and had transient full-body paralysis.

It became clear that it wasn't safe for me to live alone anymore, so I decided to take a gap year to get a handle on this.

This fall, I was finally able to get an accurate diagnosis. I have mild chiari malformation (brain tissue slipping into my spinal canal) and severe craniocervical instability (my connective tissue allows for too much movement at the point where my head meets my neck). Any time I moved at all, my vertebrae were slipping all over the place and compressing my brainstem.

My only treatment option was surgery, which I had on 7/18. Everything went great. The surgeons removed part of my skull to make space for my slipping brain tissue, snipped the nerves in my head, and fused the base of my skull to my neck.

I'm hoping to return to school in the fall, but six weeks is not a lot of recovery time for a major surgery like this. I may end up having to take another gap year even if I only need a few more weeks to recover because Princeton doesn't allow gap semesters for underclassmen. *[Note: She's starting school this week. –ed.]*

I'm sorry for all of the messages I missed this year. This condition has made reading and using social media really hard. Also, thanks to everyone for your prayers and well wishes.

I want to share this story now because I have finally arrived at disability acceptance. I've gone out of my way for years to hide my disability because I was in denial about how sick I was. I didn't want to make a mountain out of a molehill, so I ended up making a molehill out of a mountain. I wish illness wasn't a part of my life, but it is, and I'm not scared to share that anymore. I've learned to accept EDS as part of who I am, and I'm ready to start sharing that.

*You removed my sackcloth and clothed me with joy, that my heart may sing your praises and not be silent. Lord my God, I will praise you forever.*

*(Psalm 30:11,12)*



# Thanks for Praying!

God is still on the throne! Please continue to intercede with us for

- our Sunday morning Connection Circles (small group discipleship classes for all ages),
- our summer interns, in their next steps with God,
- our preparation for fall ministries, in both the church and the academy, and
- financial provision for the ministries and missionaries we support.







God really blessed at our community outreach last week! Thanks for praying with us!

## We're praying with you!

If you're on our mailing list\*, you're on our prayer list! If there's anything specific that we can join you in praying about, please let us know.

We love hearing from you! Stay in touch, to let us know you're out there!

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\* **Important:** If you'd rather not be on our mailing list, we won't be offended! Just call or drop us a note, and we'll remove you. (We'll still keep you on our prayer list!)

If you'd rather receive this letter via e-mail, please let us know!

## Did you know?

Frances Perkins, the first female Secretary of Labor, served in that capacity longer than any other secretary (12 years and three months, under FDR). She's also recognized as a saint in the Episcopalian church, with a feast day on May 13<sup>th</sup>.

**"Speak up for those who cannot speak for themselves, for the rights of all who are destitute. Speak up and judge fairly; defend the rights of the poor and needy." (Proverbs 30:8,9)**



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