Women's Brunch Talk-April 18

Disclaimer: this is an automatically generated machine transcription - there may be small errors or mistranscriptions. Please refer to the original audio if you are in any doubt.

Date: 15 May 2015

Preacher: Wanda Schellenberg & Sophia Underhill

[0:00] Good morning. It's really so lovely to see all of you here. Well, our story began almost exactly 18 years ago.

My husband Owen and I had two children. Our son Adrian was 10 and Sophia was 7. And I was pregnant with our third child because I had gained only a small amount of weight.

An ultrasound was done about six weeks before our baby was due. Your baby is very small was the phrase that kept being repeated over and over to us.

And this triggered a number of tests and meetings with our midwife and a perineutologist, a geneticist, and genetic counselors over the following weeks.

My husband and I are musicians, so at the time we were fairly in the dark about medical scenarios like this. I was just thinking, well, people are all shapes and sizes.

[1:08] You know, maybe babies could be too. But a final test confirmed that our baby had a genetic disorder. It's called 5P-minus.

So it refers to the fifth chromosome. The top section is called P, maybe for peripheral. I don't know why. And the minus means it's broken.

Yeah. So literally there's a piece of genetic material missing in every chromosome, number five, resulting in hundreds of missing genes in millions and billions of cells.

Owen and I still remember an agonizing meeting with a geneticist. We were in shock and had trouble taking in the information.

With little medical knowledge ourselves, we were just hanging on his every word. What does it mean? We kept asking. He couldn't give us specifics, but he spoke about a constellation of possible abnormalities.

[2:13] He also mentioned an extra little bit of unidentified genetic material that was stuck on the end of the same chromosome. Might that be helpful to our baby?

We asked. He shook his head. Equally deleterious, he said. And the young genetic counselor pushed a little box of hospital Kleenex across the table to us.

During the preceding weeks of tests, we tried hard not to let our imaginations turn to dark thoughts. There was no history of genetic missteps in our families.

So how could we possibly have been prepared for news like this? We learned that 5P- affects about 1 in every 50,000 newborns.

It's characterized by physical and mental delay, skeletal and gastrointestinal abnormalities, low muscle tone, vision and hearing problems, and so on.

[3:15] These are the issues that not only loomed in our minds, but they came to entirely during this time represent our baby. The remaining few weeks of pregnancy were sad and difficult.

At times I felt fatalistic, like it was just our lot. You know, under the circumstances it was a rather passive-aggressive attitude toward God about our situation.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

I was really afraid that this baby would be so other that I would not somehow be able to take her into my mother heart.

I really wished that I had not done all those tests, that I didn't know about the constellation of problems that were ahead. My husband was experiencing his own kind of anguish and really struggled with not having the kind of community that could help him grapple with his heartbreak or with whom he could openly pour out his sorrow.

Owen and I supported each other as best we could. Our minister and pediatrician and midwife visited us at home, and friends and family sent good wishes and prayers.

[4:36] Only later did I realize how important these prayers were, how they protected me as I went through a spiritual desert. I even admitted something terrible to my husband, that I did not want this baby.

Something I thought I'd never say. Something I regretted saying. Our daughter Lynn was born on her due date, weighing three pounds, one ounce.

She was quiet and floppy, and it was discovered that she had a small cleft in the back, of her mouth where the palate becomes soft, but she was breathing on her own.

When Owen brought her over to me, he looked at her and said, this is certainly a baby we can love. Those words washed over me, and I think of them now as God's first gift regarding Lynn.

They were incredibly reassuring words, and they said something important about my husband's character as well. We were truly relieved to finally see her, and now instead of trying to grapple with the monster of our imaginations, we had this tiny doll-sized child, and a job to do.

[5:58] So I was seven years old when Lynn was born, which I'm quite pleased about in retrospect, because it means that I have memories of her birth.

I have just two memories from before her arrival into the world. The first is coming home from school one day, finding my mom in tears sitting beside the telephone, not understanding what was wrong or how I could help.

The second memory is being very confused about what my new sister was going to look like. I was told she wasn't going to look entirely normal, but in my child's mind, I didn't know what this meant, and anticipated her looking quite strange.

My next memory is being woken up by my cousin Jeff on the day Lynn was born, being told my parents had gone to the hospital to have the baby, and I was so excited.

Jeff took my brother and I to the hospital later that day, but we weren't allowed to go into the room in the ICU where Lynn was. So all we could do is peer into the room through the window at my mom and this very tiny three-pound blob.

[7:10] She was hard to see around all the wires, the tubes, the machines, the incubator. And in fact, I was too small to even see through the window and had to sit on my cousin's shoulders in order to get a glimpse of my new sister.

It was a whole week before my brother and I were allowed to hold Lynn or even be in the same room as her. When we finally were able to meet her, we had to put on hospital gowns, my brother Adrian had to wear a face mask because he'd been sick, and the nurse had to give us special lessons on how to hold Lynn carefully since she was so small.

I was so pleased to meet Lynn, and I loved her immediately, as you can tell. When we finally brought Lynn home, the challenge of figuring her out and caring for her seemed like a family challenge that we all had to do together, at least in my mind.

We all learned the tricky task of feeding her through her nasal gastric tube, as well as with a special bottle. And I distinctly remember that Adrian, my brother, was the first person to feed her 10 cc's in 10 minutes, which was a record.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

When Lynn pulled out her nasal gastric tube in her sleep one day, we were in an odd way delighted because we saw it as the first hint of her strong, distinctive personality.

[8:32] She was so tiny, and I remember feeling somehow proud and fiercely protective of her tininess, her vulnerability. She was so unbelievably precious, you couldn't help but love her.

I left the hospital after a couple of days after Lynn was born, although she stayed for a few weeks.

But before I was discharged, a doctor came and sat beside my hospital bed and asked me whether I was planning to eventually take Lynn home.

I was surprised by the question and deeply embarrassed. Can you imagine being asked such a question after having a healthy baby? Or is this just something they ask mothers or children with serious challenges?

Is it if they suddenly become a commodity? I heard the answer, yes, of course we want to take her home as soon as possible.

[9:43] Those first few days had been thankfully busy responding to Lynn's immediate needs as you do with a newborn. But the bigger issue, the one with societal implications, was coming at me like a slow punch.

The issue of her disability. And I was coming smack up against the prejudices that I previously didn't think I had. No one would want to give birth to a child with disabilities, although I have met some extraordinary parents who have adopted such children.

But Owen and Adrian and Sophia showed such uninhibited acceptance of this baby that it was easy to follow their leave. I was humbled. Already God had gifted me with a deep love for the child that a few days before I was afraid to see.

Okay, that's the really hard part. The first few weeks of Lynn's life, we simultaneously felt sort of emotionally bruised, but also truly joyful all at the same time.

It was kind of a paradox. But sadness faded pretty quickly because we really didn't know what to expect from her. We just thought that literally anything she could do was terrific, whether it was making a funny face or kicking off her blanket.

[11:16] And we all have a special memory of the time and exact place where Lynn first left. Really, God has given her many abilities to learn and to remember, to recognize people, to see patterns, to trust others, to give and receive life and to enjoy life, to give and receive love and enjoy life.

I wish the geneticists had been able to tell us all of that. So as we settled into a routine with Lynn, certain challenges presented themselves.

For instance, Lynn threw up a lot for years and years. She had such bad reflux that she would throw up multiple times a day, even through her nose.

It was incredible. We had absorbent claws strategically placed all over our entire house. You know how people adjust to a new normal?

Well, this was our normal. It stopped phasing us after a little while. I remember I was holding Lynn one morning before school and she threw up. I didn't think much of it until I went to school and some kid pointed at my sweater and said, what's that?

[12:38] I looked down at my sweater, calmly replied that that must be my sister's vomit. When he responded with a loud, ew, I had the realization that my normal probably wasn't the same as other kids my age.

But I don't remember particularly minding. What I did mind was all of Lynn's caregivers who were constantly in our home. As an introverted and emotionally volatile child who had frequent meltdowns, I felt vulnerable when tears and emotions I couldn't control exploded to my horror in front of Lynn's caregivers.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

I wished our home was just our own. Yet Lynn's presence in our lives has always involved inviting others into the messiness of our lives and our home because we needed other people.

We always have. And we needed a community to come alongside us. Doing it alone was and is still too much. Lynn's vulnerability has made us vulnerable too and I'm comfortably aware of how much we need other people.

Yes, as Sophia mentioned, asking for help is something we've had to do from early on. There are times when the physical demands of caring for Lynn leave me absolutely bone weary when I could literally fall asleep in a minute and yet there are hours to go before the day is over and no assistance in sight.

[14:13] With no family close by, we've always had to hire help. Living with strangers has been a big experience in itself. As I've thought back over the almost 18 years, I counted 25 helpers we've hired.

Each one of them has had different strengths and interests of course so it can be tricky to find a good fit. Years ago, I remember one neighbor girl I hired who actually left Lynn alone in the house as she dashed home to get a cigarette only to come back and find she had locked herself out.

But, the good news is more recently we've had wonderful caregivers who've been great at finding unique ways to play with Lynn or introduce her to the local community.

More often than not, as we gain trust and get to know each other, we become honest friends. still, it's hard to ask for help all the time. I still have to get the okay before I take a shower or make a phone call longer than three minutes.

But if I can hold all of that in perspective, it does remind me that God, you know, that community is God's idea and he really does want us to be dependent on him and on others.

[15:38] Those early years with Lynn were like, a bit like trying to feel our way around in the dark. She had a few surgeries, one to correct the cleft palate and some tubes put in her eardrums because of frequent ear infections, but it was the complexities of feeding her that was so challenging, is so challenging.

I remember that shortly before Lynn was born, we were discussing girl and boy names with Sophia and Adrian and I said that I really like this name if she were a boy to call her Lucas and right away Adrian said, no, Lucas, Mucus, Pukus.

That kid's going to get teased mercilessly. I still like the name Lucas, but in light of all the mucus and pucus, maybe it's better to get it with me.

It took years of discussing and logging and videoing all that mucus and pucus and charting her slow weight gain and sending scopes down her esophagus to unravel the cycle of stomach acid leaking up into the esophagus and all the consequential bleeding and swelling and even more mucus production to finally get the gastroesophageal reflux disorder diagnosis and the corresponding medication that keeps it manageable more or less.

There have been suggestions over the years that perhaps Aline would benefit from a G-tube going into her stomach or even a J-tube into her upper intestine, but you just have to witness Aline's joyful reaction to food to understand why it was so important to find a way to feed her orally.

[17:39] Initially, she ate like a bird and we'd give her about an eighth of a teaspoon out of a little shot glass. Now she eats about half a teaspoon at a time as we carefully listen to her breathing and swallowing and watch her eyes in case they water indicating aspiration.

as Aline approached school age, we were naturally apprehensive. She was barely 20 pounds, but I knew she was ready for more stimulation.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

Of course, kids stared at her at first, but once their questions were answered, they too accepted this new normal that Sophia was talking about and happily learned sign language and offered to help push her wheelchair and so on.

We love it when kids or adults ask questions, by the way, we're just putting that out there, because it's really the only way to get to know her and to feel comfortable around her.

Around this time, tests showed that Aline's combined loss of both vision and hearing to the degree that neither of them could be used as a primary source of learning at school.

[19:01] This put her in a category called deaf-blind. Ironically, this was a really important turning point for us, like coming to a door with a sign over the top that said, welcome to Aline's world.

And very, very slowly, that door has been opening for us, gradually helping both Aline and us to understand and communicate with each other.

In the deaf-blind world, we talk a lot about sensory integration, how each sense is designed, like taste, touch, smell, hearing, vision, and also proprioception and vestibular that help you with your balance and help you navigate your body through space.

They're all designed to work in concert with each other. so if some are not working properly, the others all become more challenged. But none of us truly manages this perfectly.

One clinician I heard talking on this subject said she would phone her mother long distance and her mother would pick up and say, hello dear, just a minute, I have to get my glasses.

[20:14] glasses. Yeah, it's true, it's very interesting and it's also very true that each sense works more effectively as part of a symphony of senses than on its own.

So having a significant vision and hearing loss makes processing information very, difficult and causes all sorts of sensory imbalances and sometimes overload.

And this partly explains why Aline has disturbed sleep patterns and why she finds being upside down really satisfying, why she craves sensory experiences like being on the grass or in warm water.

She loves deep pressure and tight hugs and sometimes she needs to rock back and forth. But the most wonderful thing in this deaf-blind world was that we learned how to begin building communication for Aline, a communication system and it's for sure always an ongoing thing.

Aline's school years have been positive and fairly healthy except for one year when she had four bouts of pneumonia. In early childhood we realized she'd been born with congenital scoliosis but it wasn't until that particular year when a whole bunch of x-rays were done because of the pneumonia that the scoliosis was really noted.

[22:00] eight years ago that sort of gentle curve in her back that we saw measured about 31 degrees.

Today it is a high thoracic curve measuring well over 110 degrees. There have been x-rays, years of x-rays and appointments with the orthopedic surgeon.

She was put on a surgical wait list but by the time her name was getting close to the top of the list the curve was so severe that the surgery itself seemed to pose as much risk as the option of not doing surgery.

The surgeon was convinced it was still the right thing to do. Her deformity is getting extremely severe he wrote noting rib stacking where the ribs are actually pulled up to be more vertical than horizontal.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

and concern about the lungs and the esophagus becoming constricted. Our two pediatricians were convinced that it was the wrong thing to do citing the possibility of multiple complications during surgery and recovery.

[23:15] I know that God would have walked with us in whatever decision we made but we couldn't just pick a number out of a hat.

We had to be respectful of Aline and thoughtfully and prayerfully ask God for wisdom. There was no good option just a choice between bad and more bad.

we talked to every health professional that knew her and thankfully Erin and Amy Roberts came alongside us to pray and listen as Owen and I hashed things through trying not to get ahead of each other in this decision or disagree with one another.

Eventually they confirmed what they heard us saying though we could hardly bring ourselves to say it. There would be no corrective surgery. Aline's pediatrician gave us one final piece of advice on this topic.

Do not revisit this decision in the future she said. Just move on and enjoy her while you have her. As Aline grew in years although not substantially in size or pounds I also grew into my teenagehood.

[24:40] At this time Aline's presence in my life started to really shape me and my identity in a different way than it had before. I started realizing I was incredibly protective of the special needs community as a whole not just my sister and of all people in society with quiet voices people who aren't always heard.

I became sensitive about how others treated and spoke about people with special needs and yet unsure of how to express myself in all this. At first I became a sort of prickly fierce clumsy advocate who would merely get angry at anyone I felt was disrespecting my people.

For instance when I overheard one of my classmates in high school saying don't empty the recycling that's for the retarded kids to do I became angry and tried to publicly shame her into feeling remorse.

Not the right idea. Another time I had to suppress a strong urge to let a group of guys on the bus have it from me when they loudly made fun of a girl they knew for being in a wheelchair.

Later that day when I was angrily recounting the incident over dinner to my family and detailing exactly what I wished I said to the guys on the bus I remember my brother quietly saying to me Sophia you're never going to change anyone by yelling at them.

[26:04] You'll never get through to people by lecturing them and showing your anger. You have to dialogue respectfully without shaming being understanding of where each person is coming from especially those who've never had the opportunity to truly get to know a person with disabilities.

This conversation has always stuck in my mind. For me it represented a struggle to put away my negative emotions, my anger at the way special needs people are marginalized by our society, a feeling of victimization on behalf of Alin for this disrespect, and to use my experience with Alin in a positive way, to gently show others that Alin is valuable, she is gifted, she's smart, she's beautiful, even though our society might indicate otherwise.

Through this period in my life I also struggled with the weight of responsibility of helping out at home. I didn't begrudge the level of responsibility or wish my life was different necessarily, but I had complicated emotions as a teenager about it all at times.

My brother's friends were in our house a lot and who I thought were unbelievably cool, often saw me feeding Alin and tidying the kitchen and so on.

Not that that is all I did by any means, but one day as I was doing the dishes, one of my brother's friends told me I was going to be a good middle-aged woman one day.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

[27:36] I laughed the comment off, but on the inside it made me feel deeply embarrassed and angry that that was how he saw me and interpreted my actions.

Yet at the same time I loved Alin and our family and helping care for her was just part of my life. And I can truly honestly say that I don't wish Alin any different than she is, except maybe healthier.

A couple of years ago my parents dragged me to a sibling's appreciation event. It was put on by the Rare Disease Foundation which my dad sits on the board of.

And the point of the event was to appreciate siblings of children with rare conditions and disabilities. My dad was really excited to bring me to the event, me not so much, I was at least 10 years older than the oldest of the other siblings.

I think they had me down as age 14 on the list. I was like, no, I'm 22. I was too old to do arts and crafts.

[28:57] So the organizers awkwardly put me in with the parents where we listened to a talk from a woman who works with families of children with cancer. During the question period at the end, one of the moms who was there listening explained that she felt wracked with guilt that her younger son wanted to help take care of her older son who had special needs and her younger son would run for the first aid kit whenever her older son had seizures.

She stated through tears that she felt no child should have to deal with that kind of situation and she wished her younger son didn't try to take care of her older son. Instead of giving a response, the speaker looked at me and asked me as a sibling to offer my thoughts.

I quickly tried to gather my thoughts and figure out how to respond sensitively. It's a complicated question. To me, I explained, caring for Lynn was the only way I knew of getting to actually know her and of loving her.

and as a sibling, I didn't know anything other than life with Lynn. And so caring for her felt normal, not forced or contrived. And furthermore, if I wasn't allowed to help take care of Lynn, how on earth was I supposed to have a relationship with her?

To me, caring for Lynn is something special. It's not glamorous or easy, but it's deeply precious. Seeing her smile when she sees that I'm there, look me right in the eyes, throw her arms around my neck, grab my hand, ask to be tickled.

[30:32] These are moments I wouldn't trade. Jean Vanuie writes about this, describing a man with disabilities named Antonio. He writes, Antonio could not love by being generous, by giving things to people, or by doing things for them.

He himself was too needy. He lived a love of trust. trust. In this way, he touched many people's hearts. When one loves with trust, one does not give things, one gives oneself, and so calls forth a communion of hearts.

Through loving us this way, Lynn has changed us and made us different people than we otherwise might have been. staying united as a family, when someone is highly dependent and constant care is needed is quite a tricky thing.

There is inevitably stress and frustration. tension. I know of a woman who tells of keeping her severely disabled son a secret for a year because of shame and guilt.

It can be hard to care for each other and sometimes even hard to agree with each other on how best to care for the disabled child. Some families don't make it.

[32:03] There are times when I struggle to do my job cheerfully and times when I am so wrapped up in the myriad details of Alin's life that I am tempted to micromanage everybody and everything.

But Jesus knows me well and has shown me sweet forgiveness for running ahead, crashing around with my fears and being doubtful about his provision for each day.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

I trust now that I am in this place because God thinks it's a good idea. By God's grace, Alin's presence in our family has brought us closer.

I've learned from my husband not to live with regrets, not to be troubled by differences and things that don't conform. I look at Adrian and Sophia and see a lack of the fear of disabled people that I had when I was younger and much of the work that they've chosen to do as young adults also reflects their heart for those who live on the margins of society.

Alin has had a creative influence for Adrian, who has made two pieces of art about her, one visual and one in the form of song that he wrote and recorded for us.

[33:22] From Sophia, my kindred spirit, I am learning many things, to not make excuses for how Alin is, to not overthink everything, and to please not get burnt out.

A little while ago, I was considering taking a sewing course in the evening, humming and hawing, and she said, well, just do it. It'll help keep you sane. Serious implications, but kindly meant, I'm sure.

When Sophia was quite young, she said, I think God sent him to cheer us up.

It is, of course, exactly right that we cannot engineer our own happiness by avoiding the difficult things that come our way. Author Desmond Hunt writes, such is our blindness that often we dread most the things that contain the most possibility a blessing.

A Lynn is indeed a blessing. She's like a shy flower lifting her head to bask in the sunshine of those who love her, reaching out her thin hand to friends and sometimes strangers.

[34:43] Sometimes just her quiet presence touches people. Recently, I was sitting between two men in a busy waiting room at the driver's licensing bureau, and I pulled the Lynn's wheelchair in to face me.

First, one man and then later the other man started talking and telling me their stories. stories of a family member with a disability, story of childhood abuse at school, and another story of being a recovering alcoholic.

I mean, it was not your usual waiting room chit-chat. They were literally talking to me while looking at Lynn somehow feeling safe in the presence of her vulnerability.

Though Lynn is certainly a mystery, I think she is an amazing girl, doing what she can with the body that she was given, trying to figure us out as we try to figure her out.

In her way, she is complete, with a personality and a great sense of humor, and a soul made by God. I am in awe of God's great and wild imagination, using her physical disabilities to show me my spiritual disabilities.

[36:13] Jeffrey Sitzer writes a lovely book on prayer, and he says, prayer can be risky. God might use the very situations we are asking him to change as tools to transform us.

So, as we near the end of our talk, I want to speak a little about who Lynn is today, and what she's shown me.

We've talked about some of the struggles associated with life with Lynn, but to me, part of representing Lynn in a way that grants her dignity is describing her many gifts as well.

Lynn is truly one of the most social people I know. You may think it odd I say this if you've met Lynn before, but I honestly know this to be true. She loves when there are lots of people at home and gets excited to see people she knows.

Lynn wants to eat when others are eating. She even laughs when others are laughing, even though she doesn't know the joke. laughs. It's really fun. Lynn has a phenomenal sense of humor, and once she happens upon something that she thinks is funny, whether it is putting her tiny feet in my big shoes, seeing the reflection of light on the surface, a Kleenex blown toward her face, she can giggle for a long time.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05

[37:40] Lynn's moments of pure, unbridled joy, they lift all those in her presence, and this is one of her many gifts. Another is drawing others into community. Lynn is more popular in commercial drive than any of the rest of our family.

You can't get very far without someone wanting to say hi to her, whether it is a cashier at one of the grocery stores, a neighborhood kid, or one of the many homeless men and women who know and enjoy Lynn.

Lynn gathers people around her in a strange sort of way, wherever she goes. I could go on and on about Lynn's many gifts, but I want to share what Lynn has shown me and taught me about living differently and living counter-culturally.

Wyndham Thiessen, who is the director of a large community in Saskatoon, wrote about the counter-cultural nature of people with disabilities and the challenge that this poses to their inclusion in our society.

He says that there are two ways we can go about trying to close the gaps that exist between people with and without disabilities. One approach, he writes, is to support people with disabilities to find their place in the so-called normal world, the world of success, competition, and power.

[39:05] But this approach allows us and the normal world to remain substantially unchanged. The other approach, he continues, is to meet this disabled person on their own ground, opening ourselves to change, loosening our tight grip on the normal world's values of success, competition, and power, since these very values are what often leave people with disabilities on the margins.

our society places high importance on intellectual ability, power, beauty, social standing, good education, capability, the ability to be independent, self-sufficient.

We all consciously, but mostly unconsciously, I suspect, strive after these things, judging both ourselves and each person, based on their ability to embody these values or not.

And while these values are not inherently bad in and of themselves, I think they become idols for us, to the extreme detriment, not only of ourselves, but of all those on the margins, like Alim, who cannot achieve status, power, success, in the way that our societies define these things.

To me, I know what my idols are. They're getting good grades, a good education, being smart in the eyes of the world. I've even convinced myself that I was named Sophia, which means wisdom, because I was destined to be a person.

[40:46] It's making something of myself that is impressive to others, even sometimes being considered conventionally beautiful. yet, when I look at Alim, and I see her simplicity, her joy, her trust, her beauty, her capability, I see that she shows me another way, another way to live, that involves dismantling these idols, and opening my heart to God, laying both my gifts and my weaknesses at his feet, and acknowledging that his love and approval are the only love and approval that I need.

Alim helps me to put aside my individualism, my need for power, my need for belonging, and I can see that God has and is continuing to transform me through Alim, calling me every day to live a life that is far more counter-cultural than I'm comfortable with.

Downloaded from https://yetanothersermon.host - 2025-12-11 03:04:05