

Part B: Exploring Responsibilities and Engaging Issues



Genetics and Congregations: What should we do?

B1

Gathering

HYMN

(See hymn suggestions on p. 119)

PRAYER

Good and gracious God, giver of all good gifts, we give you thanks for the gift of your Word, of each other, and for your Church. As we seek to understand, give us wisdom and patience. Help us to listen thoughtfully with profound respect for one another. Instill us with vision and imagination, humility and forgiveness. In Christ's name we pray. Amen.



HEARING THE WORD

Ephesians 4:1-15

DISCERNING THE WORD

Silence

Discernment

What did you hear in this reading? Is there a word of God for us here?

Introduction

Session summary

This session encourages conversation on how congregations might address genetics or genetics technology issues today. We must be prepared to understand enough of the science and to listen to the potential implications posed by the application of genetics and biotechnology in order to consider how we, as Christians, might respond to the questions. Within congregations are families affected by the chronic nature of genetic conditions, people living in the midst of biotechnology they had no idea would impact their lives, and people called to advocacy for change because of their belief that in God's kingdom life should be different.



Real life stories

As you read these stories, ask yourself: What could our congregation do?

1. Belinda and Cody

Amalaya and Zach are truly enchanted. It seems like just yesterday that Belinda was born, beautiful with all that dark hair. Maybe it was just yesterday. Everyone in the hospital is worried and won't let her go home, but she is just a little slow to eat. She is so cuddly. They keep saying something about low muscle tone—how would you feel after a two-day labor. No wonder she seems floppy, she will perk-up soon. Just wait until she meets Cody. Already at six weeks he is holding his head up and looking right at his mother! What luck to have a best friend with a baby at the same time as you!

Nine months later....

Amalaya and Zach now have confirmation that Belinda has SMA, spinal muscular atrophy. She has been sitting on her own but has lagged behind Cody. Still, her eyes flash and she giggles and laughs and babbles all the time. Somehow that makes some of this bearable. How could she have SMA? No one in the family has had anything like this. Amalaya and Zach learn that they each carry a hidden recessive gene and have a chance (actually 25% chance) that future children will have SMA.



In this passage, the image of Christ rising and giving grace as a gift (Eph. 4:8-9) comes from Psalm 68:17-20, a hymn of praise as the Lord God ascends the holy mountain, receiving gifts from people and giving the gift of salvation.

How has Christ's gift of grace strengthened you to keep the unity of the Spirit in the bond of peace? (Eph. 4:3)

Spinal muscular atrophy is a disorder that affects the control of muscle movement. It is caused by a loss of specialized nerve cells, called motor neurons, in the spinal cord and the part of the brain that is connected to the spinal cord (the brainstem). The loss of motor neurons leads to weakness and shrinkage (atrophy) of muscles used for activities such as crawling, walking, sitting up, and controlling head movement. The condition progressively worsens with time.

Alpha-1 antitrypsin deficiency is caused by the lack of a liver protein that blocks the destructive effects of certain enzymes. The condition may lead to emphysema and liver disease, and, in rare cases, skin disease..

Five years later...

Cody is headed off to kindergarten! Belinda has already been “going to school,” first as part of the birth-to-three program and later in the preschool program for children with special needs. The house is finally completely wheelchair accessible. What a challenge! Next project is the church! Zach’s sister is asking about the genetics of SMA. She and her husband are expecting and her OB asked if she wanted prenatal diagnosis for SMA. There is screening to identify carriers of SMA. Who would want to know that during the pregnancy?

Twelve years later...

What a difficult weekend! Cody is graduating from high school. Does anyone remember that Belinda should be graduating, too? Is it five years already since Belinda succumbed to pneumonia? It seems like yesterday. At least no one else in the family has had to endure such lasting pain.

2. Transgenic Seed

The Smiths and Joneses are both members of Rural Small Town Lutheran Church. Mr. and Mrs. Smith live on an acre of land in the country with their two children. They both have full time off-farm employment. One of the children, Bobby, has severe food allergies that can be exacerbated by hidden ingredients in processed food. In an attempt to reduce the chance for reactions, they have cultivated a large organic garden. They use the produce fresh, as well as can and freeze it. They also installed special air filters and placed wood floors throughout the house. Bobby has had fewer reactions over the past year and they are thrilled.

Mr. and Mrs. Jones live across the road from the Smiths. They also have two children, and run a good sized commercial grain farm with a modest livestock operation that keeps them both busy nearly year around. They have no employees except for a retired farmer who occasionally helps during planting and harvest. One of the children, Jenny, has a severe disability. Their budget is severely strained by the costs of giving Jenny the best care and providing her with opportunities for a productive future. They really can’t imagine doing any less for Jenny.

The field representative of Shoots and Roots (a fictional company) has offered the Joneses the opportunity to raise genetically modified (GM) seed, which would provide an additional \$6,000 a year with little additional cost.

Joe Smith hears about GM seed next door and is livid. Will pollen from the GM crops reach their garden and contaminate their plants? How can he know that his produce is safe and won’t lead to allergic reactions for Bobby?

3. Insurance Fears Lead Many to Shun DNA Tests

Victoria Grove wanted to find out if she was destined to develop the form of emphysema that ran in her family, but she did not want to ask her doctor for the DNA test that would tell her. She worried that she might not be able to get health insurance, or even a job, if a genetic predisposition showed up in her medical records, especially since treatment for the condition, alpha-1 antitrypsin deficiency, could cost over \$100,000 a year. Instead, Victoria sought out a service that sent a test kit to her home and returned the results directly to her.

Victoria did not tell her doctor when the test revealed that she was virtually certain to get emphysema. Knowing that she could sustain permanent lung damage without immediate treatment for her bouts of pneumonia, she made sure to visit her clinic at the first sign of infection. But then came the day when the nurse who listened to her lungs decided she just had a cold. Ms. Grove begged for a chest x-ray. The nurse did not think it was necessary.

“It was just an ongoing battle with myself,” recalled Ms. Grove, of Woodbury, Minnesota. “Should I tell them now or wait till I’m sicker?”