Hello, my name is Cora and I have a special heart. I have HLHS, Hypoplastic Left Heart Syndrome.

The reason I am doing this is because I don't want to keep HLHS a secret. This is a picture of me meeting First Selectman Edelson of Southbury and telling him about CHD Awareness Week.

CHD means “congenital heart defect”, and HLHS is one of them. I also have a proclamation from the Governor's office.
Lots of people have things that you can't see, like my special heart, special lungs like cystic fibrosis, color blindness, and diabetes for example.

Most hearts have two ventricles, left and right. I have one, just the right. The left ventricle does the most work. My heart works twice as hard because I only have the right ventricle.
There are three surgeries that help my right ventricle work better. I was one day old for my first surgery, four months old for my second surgery, and three years old for my last surgery.

I was flown in a helicopter for my second surgery at the Children's Hospital of Philadelphia, or CHOP. I only remember the one at three years old. My body had to get bigger for each surgery to work.
I take four types of medicine to help my heart squeeze stronger, for my blood pressure, and so fluid doesn't build up and my heart works even harder.

I see my cardiologist 2 to 3 times a year and have testing done. Some are: an electrocardiogram or EKG, blood pressure, a blood draw, and a sonogram of my heart, or echo.

It is really great at CHOP, and now I see another doctor nearby so I have a bigger team!
When I visit the nurses' office I get my medicine and take my pulse ox. The pulse oximeter measures my heart rate and my oxygen level.

My best oxygen is 96%, people with regular hearts have better numbers, like 97-100%. (Let someone try).

I brush my teeth to keep my mouth healthy and chase away germs because getting sick isn't good for my heart.
Now this the same for everyone - we all need to drink lots of water to stay hydrated and healthy. My heart works harder so I carry a bottle around.

Sometimes I get tired easily and I need to rest, but I can run really fast and keep my pace up.

Because of the surgeries, I couldn't do the exercises other babies did so had a hard time with balance. I get hot and cold more easily.
I do horse riding to help with my balance and I am really good at trotting now.

I am really brave and strong for my little heart. I can run, play piano, all sorts of stuff!
What you need to remember for your heart:
Eat healthy
Drink water
Exercise
Good sleep at night
Brush your teeth
Don't smoke
Talk to your doctor about how you feel
Quiz: What's my heart condition name?
Answer: HLHS, Hypoplastic Left Heart Syndrome.

Quiz: What's my best oxygen.
Answer: 96%

Quiz: Is my right or left ventricle missing?
Answer: Left

Thank you for listening to my story about my heart. I hope you enjoyed it. Now you know about HLHS.