Objectives of Unit

In this unit of study, students will conduct individual research to understand the causative effects of a specific genetic disorder. They will create an educational power point outlining the clinical diagnosis, symptoms and recommended therapies. They will then communicate through email/blog by posing three questions to a student (PEARLS Project participant) living with the disability. Dialogue would include health issues, social issues and career/school issues that may arise as a result of the disability.

Timeline

Student Activity	Criteria (see attached rubrics)	Designated Time
Research and Research Paper	Gather information from references, internet sources and publications. Construct a three page paper with references/citations.	One lab period (2 hours) plus additional time at home/outside of class up to one cycle (1 week)
PowerPoint Presentation	Create and present an informative PowerPoint presentation using research. (Maximum of 10 slides including references/citations)	One class period (1 hour) for creating PowerPoint and one lab period (2 hours) to present/listen to peers.
Formulate Questions	Use research papers and PowerPoint to formulate three questions. Edit and submit questions to Project participants.	Half class period (30 mins)
Receive Responses	Read responses provided by participants and revise student knowledge and understanding of living with disability.	Half class period (30 mins)
Follow-up Questions	Use new understandings and research to ask follow-up questions.	Half class period (30 mins)
Reaction Essay	Write an essay describing how the research and interaction with participants of the project has changed their perceptions of persons with disabilities and how they cope with every day activities.	Homework assignment (one week to complete)

Resources, Media and Technology

Computers (internet access), library references in science/genetics, PowerPoint®, class textbook.

For Kaitlin
From Amanda and Joyce

1. Do you play any sports or do you have a hobby?
2. We have learned that there are many different symptoms of Marfan Syndrome. What are some of the symptoms that you have?
3. Do you spend a lot of time going for treatments and/or therapies?
4. Does anybody else have Marfan Syndrome in your family? Are they able to help give you advice or guidance?

1. I do not play any sports, mostly because I'm not interested in them, but any contact sports are not recommended for people with Marfan, because of the risks involved to my heart, and joints. I do have hobbies, however. I love to play the guitar, and sing. I love photography, and I spend a lot of time with my friends.

2. There are many symptoms of Marfan. I have an enlarged Aorta, Scoliosis (a curve in my spine), weak joints, poor vision, and a few other minor characteristics, like flat feet, and long limbs. That's most of my symptoms.

3. Once a year, I see a Cardiologist, a doctor that specializes in the heart. He just checks to see if my Aorta has gotten larger, to make sure that it isn't so large as to risk a dissection(the aorta tears, making it almost fatal, if not caught.) I am on a pill called a beta-blocker, which helps regulate my heartbeat, which can slow the growth of my Aorta. That is all I do, there are no other treatments I use, and I don't participate in any therapies.

4. I have an Aunt & a Cousin with Marfan, but they do not have much education, and as much as I try to teach them, they don't really see it as serious as it is. They get screened for Aortic Dissections every year though, which is all I can ask for, I guess! My grandfather also had it, and my Mother, but they passed away in 2002 and 2006. My grandfather to cancer, and my mother to Aortic Dissection.

Hi Sandra: Here are Ashley's responses to the student Pearls questions.

1. What is the biggest challenge that you have from living with this type of dystrophy?

1. I face many things from how I'm gonna do things the safest, to getting ready, to drinking or eating. I would say the hardest thing for me is choking when I'm eating and drinking. The disease causes a timing issue in my throat; which makes the drinks and food go down the tube leading into my lungs instead of where it is supposed to go. It is extremely embarrassing to be sitting at lunch, take a bite of sandwich, or chips, or whatever, and just randomly choke and have a cough attack in the middle of eating. Basically, I overcome this by, focusing when I swallow either food or water.

2. How do you approach people who may be uncomfortable when meeting you for the first time?

2. I approach everybody as being myself. If they can't accept me, wheelchair and all, then that sucks. Between everything going on I want people to accept me for me. Yes, I'm nervous and uncomfortable at first, but I've learned to just be myself and things will go a lot better. If both people are themselves from the very beginning, it's a lot more smooth sailing with less complications about not being yourself. Which causes more people to judge you based on appearance than your personality.

3. Are you nervous about meeting other people, especially boys?

3. Yes! Especially boys! I always have the feeling that people only see the wheelchair and physical appearances rather than my personality. Even with everybody, I feel like they're judging me on the wheelchair. I try to just keep telling myself to keep my head high and if I'm just myself then that's what people will see. But that's easier said than done. When it comes down to it, the people worth fighting for, are the people who will fight for you. I would do anything to be able to walk and "impress" a guy that way, but I can't, so I'll just have to work harder to impress people with my personality. It may s

4. Is swimming an exercise or therapy for you?

4. Yes! Swimming works all your muscles and since there is no gravity in affect in water, swimming is wonderful exercise. Most people think that because we are in wheelchairs, means that we can't swim. But, swimming is one of the best thingss we can do to keep the strength that we have. Keeping our strength is the most the most important thing and swimming helps us do so.

For Arielle (Albinism)
From Olivia, Michel and Stephen

1. We have learned that your condition is often the reason for poor eyesight, do you wear glasses?
2. Being a teenager, are you able to drive?
3. Are you ever nervous to meet new people because they might judge you or the way you look?
4. Is it hard / a chore to protect your skin from the sun?

Dear Olivia, Michael, and Stephen

1. I do not wear glasses. I also tried to wear contacts. I started wearing glasses when I was two years old.. During the second semester of my freshmen year I realized that my sight with my glasses was the same as my sight without glasses (20/200 right, 20/250 left). So I just stopped wearing them. I usually will bring sunglasses to school and wear them during class to protect my eyes from florescent lighting.

2. Yes, I am able to drive, but I do not have my license. I have to get a special license. I cannot drive with glasses so I will have to drive with bioptics. Bioptics are glasses with a magnifier or magnifiers mounted on the lens/lenses of the glasses. I plan to get my license in a year or two when I'm in college and have more free time.

3. In general I can be very shy, but I am never upset if someone asks me if "I am albino?". I don't really care if people judge me by my appearance. Most people don't know how to treat someone who is "different". Sometimes someone will walk up to me and ask, shyly , if I am an albino. They are usually shocked by my reply. I respond by saying "yes, I am albino" in a unflustered tone.

4. It isn't difficult to protect myself from the sun. I usually use SPF 70 if I plan to stay in the sun for a couple of hours. I wear Koolabar/Solumbra (UV protective clothing) when at the beach or boogie boarding. I usually like to go outside after 4 PM when I'm at the beach.

I hope this Information helps,
Arielle

For Byron (Sturge-Weber Syndrome)
From Cait and Colby

1. How is your basketball season going?
2. We learned of the many symptoms of Sturge-Weber and were wondering what are some that you have that you can share with us?
3. In what ways does your family support you and your needs?

Hi Cait and Colby,

Thank you for the questions. It's cool to know that 2 kids are following my blog. It's been fun writing it. Here are the answers to your questions.

1. We lost in the semi-finals, but it is the farthest that we have ever gotten in the history of the 7th - 8th grade basketball team. You might want to hear one cool thing about someone who is on our team. His name is Amir and his dad is Mike Tyson, the famous boxer. Mike Tyson lives in Las Vegas but Amir lives here with him mom Last year Mike Tyson visited our school to pick Amir up, and I was walking around the corner and saw him standing right next to my locker. Then I went and tried to say "hi" to him and he put his hand on my shoulder and said, "My brother!"

This isn't on the topic you wanted to know about, but on the topic of famous parents' kids at my school we have the son of the Attorney General of the United States in the grade below me. I talk to him sometimes, and he's very nice. And we have the Washington Redskins' owner's daughter in the grade below me. I'm in a small school - there are 39 kids in my grade - so you really get to know everyone.

After the basketball season ended we had a bowling party and it was really fun. We thought our coach would make a few strikes, but he didn't make any. I did ok. I was falling 20 points behind everyone in my lane, but that was ok with me because I was having a good time. When I threw a ball down the lane it kept on going to the right because my strong left hand was overshooting the middle of the lane.

Lacrosse season started this week and I am going to go talk to the head of athletics and see if I can help coach the 7-8 team.

2. I have a port-wine stain that used to go down to my eye, but when I was a baby I had lots of laser surgery so now I only have a little spot on my forehead. My friends at school call me Harry Potter because it looks like the Harry Potter scar. I don't have glaucoma, like lots of Sturge-Weber kids do, and I have been seizure-free since I was 10 months old when I had half of my brain taken out, a surgery that is called a hemisphyerectomy. My right hand is in a fist because of the surgery and I have to have electrical stimulation on my hand to help open it, and I only open it myself when I yawn, but most of that is because of the hemispherectomy and not Sturge-Weber. I have a syndrome, which I really don't know that much about because most of my medical stuff has to do with the hemispherectomy instead of the Sturge-Weber, and because I really don't pay that much attention to it when I go to the doctors.

3. When I need help opening stuff like a can they jump in and open it for me. I used to have a one-handed can opener but it's broken now. My family supports me in every which way. They

try to make me do as much as I can on my own, but I tell them I just can't do it sometimes (but don't tell my mom!). I asked them to get me a one-handed flip-n-fold for clothes (http://www.flipfold.com) but I don't use it that much, but it is a cool thing to have because it looks like blue swiss cheese. I don't need that much help, really, because I am independent. I have found ways to do things with one hand, and when I don't know how, I just find a way to do it. For cooking I have measuring spoons that slide across and make it level (http://www.amazon.com/Amco-Leveling-Spoons-Stainless-Steel/dp/B001BC8FN0). I use them when I RARELY bake things because I undercook or undercook. One time I experimented making chocolate omelets and it is the worst thing ever. I don't recommend it. I ate part of it and gave the rest of it to my step dad. I didn't know at the time that is was April Fools day, and he asked me if it was an April Fool's joke! Making a bed is hard with one hand and I have to spend more time than most people do to make it. That's when I ask my mom to do the corners for me, and she doesn't like it that much when I ask her to make my bed, especially at night when she's about to go to bed. Sometimes when I need help I look things up in a book I have called, One-Handed in a Two-Handed World by Tommye-Karen Mayer, but not everything is in there.

One thing is that my parents are divorced. My mom and my step-day live in Washington, DC and my dad and step-mom live in Boston, but I currently live with my mom and step dad. I see my dad very rarely, usually when I go to Boston for medical appointments, where I had my hemispherectomy done.

I get frustrated when I can't do something, but my mom and step dad get me angry and tell me to try. But when I find out that I can do it, I am really happy and like to show people what I've figured out, so in a way they are helping me.