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Genetics with Nettie and Friends: an Exploration of Genetics in Children's Literature

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GENETICS WITH NETTIE AND FRIENDS: GENETICS IN CHILDREN'S LITERATURE

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HONORS PROJECT

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The society that exists is comprised of two main subcategories of people, “normal” and “other.” The “Other” is a group of people that can be defined or categorized as not belonging or being different in common fundamental ways from the group at the core of the society. Anyone can be classified as part of the “Other” based on identity characteristics such as race, religion, sexual orientation, gender identity, social class or ability. The concept of “Other” can also be associated with minority groups within a society, in the interest of this project, individuals affected by genetic disorders and conditions are representing the “Other”. Given that being classified within the realm of “Other” carries a negative perception, it can be assumed that no one wants to be classified in this manner and that there should be a way to eliminate this form of societal classification. More often than not, individuals try to relate to an issue through creating a personalized perception where they say, “what if it was your sibling/child/parent/friend?”. This creates not only a false standard that individuals must personally relate to another in order to be sympathetic to that individual’s situation, but a society in which there is a disconnect between empathy and open dialogue about individual differences. This disconnect creates an environment in which the majority is closed-minded to the perspectives and experiences of the “Other”. Groups of people forget or refuse to humanize others who are different from themselves, and social discourse is at risk of being destroyed.

While there are ways in which social discourse can be broken down, there are ways through which the concept of “Other” can be lessened and an environment founded on empathy can be created within younger generations. One of the biggest ways that the concept of Other can be lessened is through accurate and prominent representation in media, whether it be film, television series, or books. Providing representation of individuals with disabilities within literature is important not only for the individuals with those disabilities, but the children who do

not have disabilities as well. For individuals with disabilities, they are able to see themselves within a character, and their disability can become normalized. For children who do not have a disability, reading books about characters with disabilities can "... help young people learn about disabilities as well as how to respect and accept individual differences," (Mohammadzadeh 2017). During a study done by Mohammadzadeh (2017), students were asked to read a novel *Freak the Mighty*, a story about two characters with disabilities who work together to overcome their problems, and then their responses and thoughts regarding their novel were collected. They showed that exposing children to disabilities within literature increases awareness and sympathy for those affected by a disability as well as self-reflection surrounding the treatment of those with disabilities.

Nikolaieva (2013) argues that reading makes us better human beings. For children. "reading picture books prepares children for dealing with empathy and mind-reading in real life," (Nikolajeva 2013). Empathy does not automatically appear at its maximum capacity. Normally, empathy emerges around the age of four, and continues to grow and develop through adolescence. Therefore, emotional literacy can be shaped through the use of literature that displays a diverse range of life situations. Young children have limited diversity within their life experiences. This correlates to a limited emotional response due to limited life situations. Picturebooks offer new emotional experiences to children by exposing them to new life scenarios. Fictional narratives encourage growth of one's interpersonal communication both within the text and beyond the text. By being exposed to fictional characters who display these disabilities, children will be more inclined to sympathize with special needs individuals in real life.

Regarding the societal implications of these ideas, Ostrosky (2015) examines the effects of representation of special needs children in picture books. Not only do preschoolers with disabilities engage in peer interactions less than typically developing peers, but typically developing peers often prefer to include typically developing peers over peers with special needs. This inclusion mirrors acceptance and creates an environment where those with special needs are at risk of being ostracized and marginalized due to their disability. Children ages five to eight learn through interactions with parents, family, and educators as they read books so gaining access to classroom materials that have the ability to combat marginalization is incredibly important, if not critical to correcting ostracization

Librarians and teachers want more children's literature authentically representing those with disabilities. Cockcroft (2019) examines the statistical elements that support this claim. According to this article, "81 percent [of librarians] said they consider it "very important" to have diverse books in their collections, including titles about disability," (Cockcroft 2019). Librarians and teachers want books that contain this representation. According to a Diverse Books Survey released in 2018, "62 percent of librarians said that books featuring characters with disabilities were in demand and hard to find; 61 percent said titles with neurodiversity characters – or those with invisible disabilities – were in demand, and 45 percent said those were difficult to find," (Cockcroft 2019). Educators want children's literature that represent individuals with special needs or disabilities, they are just incredibly hard to find.

Genetics with Nettie and Friends is an exploration of genetics and its place within children's literature. All organisms are composed of genes, and those genes have the potential to cause disorders within an individual. Because of this, it is important to expose young children to

genetic concepts in order to stimulate their empathy development towards those with disabilities and normalize those with special needs. This also increases awareness about genetic disorders and their causes to the general population who otherwise might not have been exposed.

DNA is the genetic blueprint for life. It codes for the genes that help us grow, develop, and function. Much like a sentence, DNA is composed of bases that occur in a specific order to code for genes that are necessary for life. Because DNA is too big to be the nucleus unraveled, DNA is tightly coiled into structures called chromosomes. In humans, individuals develop along a normative path based on the instructions set in 46 fully intact chromosomes. However, it is possible for someone to develop outside of that normative and these mistakes can occur during gamete production or while the organism develops. This is caused by chromosomal disorders.

There are three types of chromosomal disorders. The three types are monogenic, polygenic, and chromosomal. Monogenic disorders are caused by a change in a single gene (Monogenic Disorders 2011). These are the simplest of the disorders because only one gene is involved. An example of a monogenic disorder would be sickle cell anemia. Polygenic disorders are caused by the combined actions of more than one gene (Polygenic Disorders 2004). Because more than one gene is involved, these disorders are more complex than monogenic disorders. Examples of polygenic disorders include hypertension, coronary heart disease, and diabetes. Chromosomal disorders are an abnormal condition involving the chromosomes (FAQs About Chromosomal Disorders 2017). This can be caused by a whole extra chromosome being present in the cells, a whole chromosome missing, part of a chromosome missing, or part of a chromosome being translocated and attached to another chromosome. All of these conditions can cause a chromosomal disorder. While these are more complex than monogenic disorders, they

are more visible conditions. Because of this, I chose chromosomal disorders to be the focus of my children's book. The disorders that were chosen to be showcased in my book include Down Syndrome, Williams Syndrome, and Duchenne Muscular Dystrophy.

Down syndrome is one of the most common genetic disorders. It is estimated that there are approximately 1 in 700 cases of Down syndrome every year. Overall, there are three types of Down Syndrome. Trisomy 21 is the most common form of Down Syndrome, and it comprises approximately 95% of Down syndrome cases (Data Statistics on Down Syndrome 2019).

Trisomy 21 occurs when there are three copies of chromosome 21 in every cell of an individual. This is the form that most people think of when they think of Down syndrome. Similarly, to trisomy 21, mosaic down syndrome is caused by the presence of a third copy of chromosome 21 in the cells. However, mosaic down syndrome is different in the fact that the extra chromosome is only present in some of the cells instead of all of the cells (Mosaic Down Syndrome 2011).

The third form of down syndrome is translocation down syndrome (Translocation Down Syndrome 2019). Translocation down syndrome occurs when a portion of chromosome 21 becomes translocated onto another chromosome before conception. In this form, the individual has two full copies of chromosome 21, but extra genetic material from chromosome 21 is found elsewhere in the cell. For my book, I chose to focus on trisomy 21 because it is the most common form of down syndrome, and because of that there is a high probability that a child will come in contact with someone with down syndrome at some point in their life. Some of the symptoms associated with down syndrome include decreased or poor muscle tone, short neck, developmental delay, delayed language and speech development, groove between first and second toes, sparkle in eyes.

For representation of down syndrome in my book, I chose to focus on decreased or poor muscle tone associated with having down's syndrome. While individual's need to be careful and aware of the risk of injury during physical activity, it does not mean that individual's with down syndrome are unable to participate in sporting events. Many individual's with down syndrome excels in events Special Olympics. Just because they need to be careful, does not mean that they cannot participate. Because of this, I chose to link the character with down syndrome, Luna, to soccer. Soccer is a sport that most children play at some point in their childhood. This provides a similarity that a typically developed reader can associate and find a similarity with. Because the age range of this book is at a similar age of the play-based stage of friendship development, this anchoring is incredibly important (Kail 2015). Play based friendship is founded on the idea that children have similar interests. By pairing Luna to an activity that most children have experience with, it normalizes down syndrome within that common activity. This would encourage typically developed children to include someone with down syndrome during play.

The second disorder featured in the book is Williams syndrome. Williams syndrome is rare when compared to down syndrome. Williams syndrome occurs approximately 1 in 7,500 people. This disorder is caused by a microdeletion of approximately 26 to 28 genes located on chromosome 7. The microdeletion normally begins at 7q11.23 (Williams Syndrome 2019). With that, this normally results in the deletion of the ELN gene that codes for elastin. It is currently thought that this deletion is responsible for majority of the signs and symptoms associated with Williams syndrome. Some of these signs and symptoms include: a characteristic facial appearance, hypercalcemia, musculoskeletal issues, developmental delay, excessive social personality, and being musically gifted.

For this disorder, I chose to focus on the excessively social personality element of this disorder. With this, children with Williams syndrome tend to struggle to interpret negative social cues because they are so happy and joyful. This means that a child with Williams syndrome is a prime target for bullying in a school setting. They will never stand up for themselves or report the bullying because they do not understand that they are being bullied. I wanted this to be the focus for this disorder so that typically developed children could learn this and learn to step to the defense of others if they see one of their peers bullying someone else (Williams Syndrome 2019). Because of the musical ability associated with Williams syndrome, I wanted to view this as a strength of the disorder, so I chose music for the anchoring activity associated with this disorder. Because of this, this character, Miguel, is placed in an orchestral setting. The main instrument that he plays is violin, and this is to eliminate the feminine characteristics that are associated with playing a string instrument. This not only normalizes Williams syndrome, but in normalizes men in orchestra.

The final disorder discussed in the book is Duchene Muscular Dystrophy (DMD). While this is still considered rare in comparison to other genetic disorders, it is the most common form of muscular dystrophy. It also provided the opportunity to explain X patterned inheritance in the book. DMD occurs in approximately 1 in 3,500 male births worldwide. While this disorder is more common in males, it can still occur in females (Duchenne Muscular Dystrophy 2019). Even though it is incredibly rare, I wanted to have the main science character to be female to encourage little girls to be interested in science. DMD is more common in males because it is X-linked recessive. This means that the gene that causes it is located on the X chromosome, and for a female to acquire it they need to have two copies of the defective gene. The mutation that

causes DMD occurs in the dystrophin gene located at Xp21. This is currently the largest known human gene and it is approximately 2,100 kilobases in length.

Symptoms of DMD are typically recognized between ages of three and six. These symptoms include large calf muscles in toddlers, clumsy coordination, trouble climbing stairs, difficulty getting up from the floor, and issues running. In most individuals, gradual wheelchair use begins at age 12. This means that individuals are not bound to the wheelchair, but they might need it for more strenuous activities such as walking long distance or standing long for long periods (Duchenne Muscular Dystrophy 2019). For the representation of this disorder, the character, Nettie, can only be seen waist up for majority of the book. This is meant to provide an illusion of being a typically developed able bodied child. Towards the end of the book, the reader can see Nettie in her wheelchair. This is meant to erase the stigmas associated with prominently visible disabilities by giving the illusion of her being able bodied.

Because the content of this book is heavier than standard children's books, I wanted the illustrations to not only complement the text but balance it as well. This encouraged the decision to collaborate with a student illustrator to provide illustrations for this book. The original vision for the illustrations were comic like, not incredibly rendered, and very child friendly. Madeleine Burland did an amazing job capturing this. Not only were her illustrations child friendly, but they brought the text to life and provided breathing room for dense text. Because of her artistic education, Madeline was given a large amount of creative license. However, I did provide feedback and expectations for the project. While storyboarding, we developed the ideas and concepts for each page of the book. This allowed us to solidify the projected format of the book as well. For the callouts that were going to be present throughout the book, we decided that a DNA double helix border would provide small detail that could carry the main scientific theme

throughout the book. We also decided that karyotypes would be used to visually explain each disorder in a way to compliment the text. Once Madeleine finished rough illustrations, we met again so I could approve the illustrations. Only two illustrations needed to be adjusted to provide adequate room for text placement. After receiving approval, Madeleine then went on to finish the illustrations.

Once the illustrations were finished, the book was formatted using Adobe Illustrate and Adobe InDesign. These applications were used to format the pages to meet print guidelines as well as a method of adding text to the book. I also attended a presentation by the author of *Sea Bear* who talked about her process of creating her book. She discussed the importance of text placement in illustrations and a method to move the readers eye through the book. I kept this in mind while formatting each page of the book. Once the text was added and the book was finalized, it was uploaded on to Barnes and Noble Press for self-publication. This book is now available for purchase for \$15.50 on their website satisfying one of the main goals of this project.

This book is strong in the fact that it does a great job of simplifying genetic concepts to a level that young children with no background in genetics can understand. This book provides a look into three genetic disorders and explains their genetic causes in a way that children and adults can digest and understand. This ultimately satisfies the main goal of this project.

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