Community Giving Project

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I. Executive Summary

Hutchinson-Guilford Progeria Syndrome is an extremely rare, progressive genetic disorder that causes children to age rapidly, starting in their first two years of life. Around the world, 1 in 20 million people are affected by Progeria. The Progeria Research Foundation was founded in 1999 by Dr. Leslie Gordon and Dr. Scott Berns after their son, Sam, was diagnosed with Progeria. They recognized that there were not adequate resources or medical help for children with Progeria, no place for parents or doctors to turn for information, and no source of funding for researchers who wished to be active in Progeria research. The Progeria Research Foundation (PRF), the only non-profit organization in the world dedicated to Progeria research, has a mission to discover a cure and effective treatment for Hutchinson-Gilford Progeria syndrome and other atypical forms of Progeria.

Due to the rarity of the disease and the small number of affected individuals, there is a serious lack of funding for all forms of Progeria research. Not enough is known about the disease with much more research needed. Due to the enormous lack of medical information and resources dedicated to Progeria, the Progeria Research Foundation (PRF) is hindered from reaching a cure. The primary goal of our Community Giving Project is to raise awareness and provide funding to support families affected by Progeria along with research to improve the outlook of this rare condition.

Deallaney Hudson, a seventeen-year-old student at D. H. Conley, was diagnosed with Wiedemann-Rautenstrauch Syndrome (also known as Neonatal Progeroid Syndrome) when she was nine days old. At that time, little was known about this syndrome other than that it was similar to Progeria but not caused by the same gene. Children born with WRS are born with an aged appearance, thin skin, very little fat tissue, and are typically growth restricted. Life expectancy or other health issues with these children were not widely studied or reported since there were so few children with the disease.
Deallaney’s parents were put in contact with Dr. Leslie Gordon at the PRF since this was the closest syndrome any doctor knew of with an organization that could possibly help. The PRF banked Deallaney’s blood and sample skin tissue and over the years created a cell line to study her genetic profile compared to typical Progeria children. With the help of Deallaney’s cell line and those from other children around the world, the PRF scientists determined that Neonatal Progeroid Syndrome is caused by a genetic mutation of the PoLr3a gene. Without their help, we still would not know the cause. For this reason, Deallaney’s parents have always felt a need to support the PRF. The Deallaney Hudson Honorary King Mackerel Fishing Tournament (DHHKMT) was started a few years ago by Deallaney’s parents, and as it grew, D. H. Conley DECA members became involved in the planning and execution of the tournament.

The DHHKMT had 3 main goals that should be accomplished to deem a successful tournament. The first was to attract 45 boats to register for the tournament. We passed this goal by registering 50 boats for the tournament. Our next goal was to raise $20,000 to be donated to the PRF to fund research and clinical drug trials in order to reach a cure. Through our increased participation and donations, we exceeded this goal and donated $23,000 to the PRF. Our final, and perhaps most important goal was to educate our community about Hutchinson-Guilford Progeria Syndrome and other a-typical forms of Progeria. This was accomplished through our social media pages, reaching our audience of...
over 700 people. With increased public awareness, the future for Progeria patients will become brightened for generations to come.

The DHHKMT had a five-month timeline to prepare for the tournament from July to the tournament date in November. To begin with, the leadership team decided the tournament would be held at the Big Rock Landing in Morehead City, North Carolina. Then, a budget was created to be as small as possible while still ensuring that all expenses would be covered; room was allotted for unexpected expenses. The next goal in the tournament preparation was for DECA students to create a logo that would be placed on t-shirts and other tournament merchandise. T-shirts were sold during the tournament and in the weeks leading up to the tournament. After launching our social media pages, we began to push advertisements and communications for the tournament. Sponsorship forms were released in August 2021, and the tournament team formulated a banner with named sponsors. In October, volunteers were lined up and registration preparations were in place.

Registration opened on November 10th for tournament participants, with a captain’s meeting held that night to brief participants on important matters pertaining to the day of the tournament. The tournament was changed to November 11, 2021, as a result of poor weather. Moving the tournament to the alternate date not only improved fishing success but also increased community participation. Despite minor difficulties along the way, the tournament was a great success.

Following our donation to the PRF in January 2022, we continue to raise awareness for Progeria in our community. Our vision is to create a world where there is an ultimate cure for Progeria, and a world where this condition no longer hinders another child or family.