



PRESS RELEASE

City of Pompano Beach

100 West Atlantic Boulevard | Pompano Beach, FL 33060

Press Release Date: 10/28/18

**Ride for Project Alive Finish Line Reception
Fire Station 11 - 109 N. Ocean Boulevard
Sunday, November 11
3:00 p.m.**

On Sunday, November 11th at approximately 3:00 p.m., cyclists with Ride for Project Alive will be finishing a fund raising bicycle ride at Fire Station 11 in Pompano Beach that began on October 20th in Charlotte, North Carolina to create awareness and raise funds for children with Hunter Syndrome. Specifically, a promising gene therapy trial that can give kids with Hunter Syndrome the chance to grow up.

The cycling event will span 1,200 miles covering four states and is the latest effort from Project Alive that seeks to complete the funding of a gene therapy clinical trial at Nationwide Children's Hospital in Columbus, Ohio. This grass-roots foundation has already received approval from the FDA for the investigational new drug (IND).

Project Alive board members Mario and Jennifer Estevez's 4-year-old son, Sebastian, has Hunter Syndrome (MPS II). The board has been working closely with the researchers developing the drug to ensure the study continues to move forward and receives funding. The South Florida community played an integral role in helping Project Alive raising almost \$2 million in the last two years. The Estevez's live in Miramar.

Affecting approximately 2,000 people worldwide, Hunter Syndrome is a rare, genetic condition resulting in the lack of the enzyme iduronate-2 sulfatase. Without that enzyme, cellular waste builds up throughout the body and causes progressive loss of physical, and in most cases, mental function. The clinical trial targets the most common, severe form of Hunter Syndrome, causing progressive neurological decline and a life span in the early teens. In 2017, the first gene editing clinical trial ever performed, widely reported around the world, was in Hunter Syndrome, but targeted the less common, attenuated form of the disease. Researchers have FDA approval for the investigational new drug (IND) application, which allows them to proceed with clinical trials as soon as they have the funding.

Pompano Beach Fire Rescue will be hosting a finish line reception for the Ride for Project Alive riders to celebrate the completion of the ride. Sebastian's parents are participating in the last leg of the ride from Ft. Myers to Pompano Beach.

Sebastian will be in attendance at the reception. The Estevez family and other Project Alive board members will be available for interviews.