



SebastianStrong and Castaways Against Cancer Raise Funds for Sylvester Comprehensive Cancer Center

Alone in his kayak, with miles of ocean surrounding him, Oscar Ortiz thinks about his middle son, Sebastian, whom he lost to cancer when his son was just 16 years old.



Nagi Ayad, Ph.D., and Stephen D. Nimer, M.D., accept the \$200,000 check from SebastianStrong and Castaways Against Cancer.

“My kayak has pictures of children we lost to cancer,” Ortiz said. “Sebastian’s photo is on my left-hand side, where my heart is. I spend a lot of time talking to him.”

Ortiz’s commitment to his son’s legacy inspired him to complete a week-long kayak expedition recently. The South



Florida father was part of a group that kayaked 160 miles between Miami and Key West to raise funds and awareness for pediatric cancer research. It was the third time Ortiz completed the exhausting mission, but the first time he and his fellow paddlers partnered with Sylvester Comprehensive Cancer Center at the University of Miami Miller School of Medicine.

Combining efforts with Castaways Against Cancer, a local group that has been raising money to fight cancer for 21 years, the kayakers raised just over \$100,000 to help Sylvester researchers find less toxic and more targeted treatments for children with cancer. Their gift was matched dollar for dollar by Sylvester for a total research investment of \$200,000.



Oscar and Rose Ortiz with Sebastian.

“Sebastian's parents, Oscar and Rose Ortiz, along with his brothers, Oscar and Lucas, are truly remarkable,” said Stephen D. Nimer, M.D., the director of Sylvester, the Oscar de la Renta Endowed Chair in Cancer Research, and professor of medicine, biochemistry and molecular biology at the Miller School. “Their ability to channel their loss to improve the



lives of other children living with cancer in Sebastian's memory is an inspiration to all of us. We are grateful for their partnership and boundless generosity."

The common thread among the kayakers: a unique brotherhood formed at Christopher Columbus High School in Miami, where many of their paddlers are either faculty members or alumni. Castaways Against Cancer got its start in 1998 when Steve O'Brien, a teacher at the school, lost his mother and grandmother to cancer. Looking for a way to "light a candle instead of cursing the darkness," he and three colleagues paddled their way from Key Largo to Key West.

After raising \$10,000 their first year out, their grassroots effort has grown with time. In 2018, they became just the eighth team, and the first in Florida, to raise more than \$1 million dollars for the American Cancer Society

Eric Pino, the captain of the Castaways Against Cancer, calls his group "a bunch of sea hippies" who like to paddle and fight cancer. Pino was also Sebastian Ortiz's cross-country coach at Columbus High. Oscar Ortiz is also an alumnus.



Sebastian Ortiz running in competition.

“Sebastian was a fine runner and an impressive kid,” Pino said. “He was mature, very introspective and kind.”

Sebastian was treated at Sylvester during his battle with a rare form of cancer called Rhabdomyosarcoma. His family was dismayed to learn that nationwide, new cancer treatments for children lag well behind those for adults, and adult protocols, often used for children, do not produce the same results. Since 1980, only four drugs have been approved in the first instance for use in children. In Sebastian’s case, there was only one treatment protocol available; a decades old regiment that included 30 plus rounds of chemotherapy, 23 radiations, and four surgeries.

“The side effects of these drugs are brutal,” Ortiz said. “Sebastian would have likely needed a heart transplant had he survived.”

After he passed, Ortiz sought out a way to honor his son’s



memory. He founded SebastianStrong as a nonprofit group specifically focused on funding innovative research for cancers that are predominant in children. Together with Castaways Against Cancer, and through the new partnership with Sylvester, they chose to support the work of Nagi Ayad, Ph.D., co-director of Sylvester's Brain Tumor Initiative, who is working to find safe and effective therapies for patients diagnosed with medulloblastomas, the most common type of brain tumors in children.



From left, Paul Kumer, Roger Dabdab, Omar Beceiro, Patrick Linfros, Steve O'Brien, Jaime Lemus, Eric Pino, Jose Mendoza, Oscar Ortiz, and Kari Linfors (rear) at the 20/20 Perfect Vision Tour.

“The transformative support from SebastianStrong, Castaways Against Cancer, and Sylvester will allow us to utilize novel computational platforms we have developed to identify safe therapies for children suffering from brain cancer,” said Dr. Ayad, who is also an associate professor in the Department of



Neurological Surgery.

Called the 20/20 Perfect Vision Tour, the SebastianStrong and Castaways Against Cancer kayak expedition took place June 7-13. Their kick-off was tempered by social distancing due to the 2020 COVID-19 pandemic. Good wishes were sent via social media, and Dr. Nimer inspired the group with a video message. Ortiz's wife, Rose, and their sons Oscar, 22, and Luke, 17, served as part of the road crew that assists the kayakers.



Oscar Ortiz with sons (from left), Oscar, Sebastian, and Lucas.

While Dr. Ayad and team do their work, Ortiz and his family will continue doing whatever is necessary to protect Sebastian's legacy, and to ensure that generations of children who are diagnosed with cancer have more effective and less toxic treatments to turn to. They say it is the least they can do for their kind-hearted son, who found a friend in everyone he met.



“Sebastian was incredibly gracious and full of humility during his battle,” Ortiz said. “He is what keeps me moving. I’ve got to make it better for the next person.”

For more information on SebastianStrong, visit sebastianstrong.org.

For more information on Castaways Against Cancer, visit Castawaysagainstcancer.com.