

Dutch Marfan Syndrome Foundation:

‘Live your Dream’ motivates chronically ill youths

Group of Dutch young patients sail from the Netherlands to Ireland

Six young people, afflicted by Marfan’s syndrome, will participate in a non-stop sail race from Scheveningen (Holland) to Cork, Ireland. With help from the foundation, they accept the challenge to gain the first prize in the special youth class race of approximately 570 nautical miles (1000 Kilometers). A risky enterprise? “Not so,” according to Olaf Oosterman (34), founder of the foundation. “I myself am afflicted by the Marfan syndrome, and because of my own physical limitations, I do understand what those of others may be. In addition, I am a licensed sailing instructor and I will be able to instruct the group and raise their ability to the level required for the race. It probably will not be an easy crossing. Much will depend on the weather that we will encounter on the way, but that also goes for the other teams.”

Physical limitations

Olaf is a born sailor. From early childhood on he has had a dream about circumnavigation of the earth. Together with his wife Marjolein he started the construction of a 14-meter (46 feet) yacht that is adapted to his height of 2.07 meters. (6 feet, 9 in). From savings and by investing their own labor, they expected to be able to complete the project in three years. Their plan? To depart in 2007 for an undefined period of time. They dreamt of far away lands and about the discovery of new and old islands.

That was until March 2004 when Olaf was hospitalized with a fever of more than 41 degrees (105.8 F). A violent bacterial infection on his aorta prosthesis nearly took his life. Nine weeks of hospitalization and six months of rehabilitation halted the construction project. Three previous surgeries, where Olaf received two artificial valves and an aorta arch replacement, were only a necessary pause in his busy life. Those procedures did not stop him, however this bacterium did. Olaf noticed that he was vulnerable. Not invincible as he always had thought. Still he persevered. He started up the construction program again but realized that his endurance level had greatly diminished and that his body often failed him.

In March 2005 Olaf received an aorta dissection from the arch to his groin. Again he was at death’s door. Upon leaving the hospital, he had to take it easy and construction had halted again. In spite of his reduced activity his aorta was expanding. The lower section of his aorta was replaced not long after that.

This process precipitated a change. Olaf new that he never would be able to complete the boat by himself. With every surgical procedure, he yielded a part of his physical condition. He also realized that his life would not last too much longer. After that, he lived continually in fear and wondered what else his body could endure. A world circumnavigation was no longer an option.

Other prospects

Olaf decided to take a different tack. He wanted to complete the boat and sail with chronically ill young people, starting with youths suffering from Marfan’s syndrome. He wanted to give them something that a healthy person could not: The urge to survive and perseverance. To do something with your life and not to see only the dark side. The dark side of his life, Olaf has seen often enough. In fact, about six times the white ER doors have opened for him and each time, he would not know if he ever would wake up again. Olaf wants to show these young people that you have to chase your dreams and that you should try to fulfill your ambitions. Don’t wait with that until you’re too old.

Meanwhile, Olaf and Marjolein have started the ‘Live Your Dream’ foundation, to complete the custom designed boat and to sail with chronically ill youths. Two professional carpenters have

been hired to continue construction. The Dutch water sport community is enthusiastic about the project and sponsors much of the materials. Olaf is moving with fair winds. Also his health is improving now. His recent scan of the aorta does not show any enlargements. He once again has gained confidence in his body and in the future. That is why he dares to take five youths to Ireland. Not on his own boat, because it is not ready yet but on a sponsored yacht, a so called X-35, a Danish sail boat of 12 meters length, (40 ft).

Thorough training

In March, at the invitation of the Netherlands Marfan Foundation, Olaf presented a paper about his dream and plans to sail to Ireland, County Cork. Five young Marfan patients spontaneously pledged to join him in the adventure, however, not without solid preparation. Olaf has sailed with the youngsters for a few weeks in the pre-season, to train them to become full-fledged crewmembers. They even did a crossing of the English Channel to get used to spending a night at sea. The crew learns how to sail, to trim the sails, to navigate, do trip planning; interpret weather reports and how to stand watch. Olaf: "Basically everyone has to learn the same things, but it may be that along the way we will train certain individuals in some specialized tasks. Physical limitations could play a role but also, some may be better in navigation while others are better in ships handling."

All of the youngsters are under intense physical guidance from the Amsterdam revalidation center. Prior to the training period and immediately prior to the race, they will take a stress test and in the mean time receive a customized personal trainings program. Olaf also wants the group to follow a course in ergonomics on board and a survival at sea course. Food supplements will be supplied prior to and after the race to have them achieve a healthy physical condition. For two months, they will receive a sponsored new American product: Vemma. This way they receive daily extra minerals and vitamins.

Irish Counterparts

On July 14, the six young Marfans will leave port at Scheveningen to tie up at Cork a few days later. Olaf: "For all of us this means exploring and changing boundaries. Also for me. I often have sailed with groups of people but every group is different. As skipper, you are responsible. Also, the territory is new for me. I often have sailed to England, but never to Ireland."

Once they have arrived in Cork, the youngsters will meet the Irish Marfan Foundation. One of the Foundation executives lives in Cork and Olaf has made contact with her. Olaf: "It will be fun to meet our Irish counterparts and to exchange experiences. Who knows what ever may come from that. In the future, Olaf will relocate the (Dutch) Foundation's Sail Area to the Mediterranean.

The intent is to have chronically ill youngsters to come and sail along for a few weeks.

Olaf: "That also is changing boundaries for them. They come to another country, with its own culture. They learn how to sail, to work as a team, live in groups of six in a relatively small space, and learn what life aboard is all about. For me this means that I still can make a small piece of my original dream come true and can supplement this in a beautiful manner. I always say: 'You must be at Peace with what you cannot do and go full speed about things you still can do'. This lesson I will send along with the youngsters."

More information on www.leefjedroom.com. The youngsters maintain a weblog with this link. (In Dutch and soon in English).

Marjolein Brandt

The Norwegian Marfan Syndrome Foundation can also help Olaf and his youngsters. With your money they can sail to Ireland. The 'Life Your Dream' Foundation still needs money, for instance for harbour fees, safety equipment, food etc. Every individual can donate money to:

Accountnumber Dutch Postbank 5425980

att. of Contactgroep Marfan Nederland

adress: Vrieswijk 5, 1852 VA, Heiloo

mentioning: *Leef je droom: race Scheveningen – Cork*

Code for foreign payments: PSTBNL21

International Bank Account Number (IBAN):

NL72PSTB0005425980