

Jamie McDonald and her husband, Brian Kamm, have learned the importance of screening all those with HHT for brain and lung AVMs early in life. This is their son's story ...

Our Story

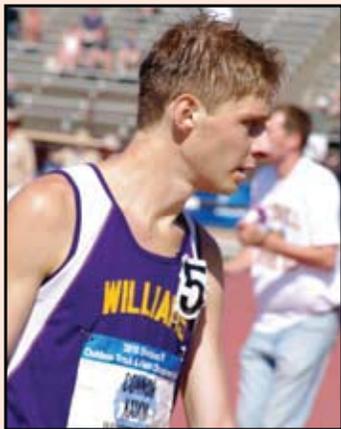
HHT Patient with Treated Lung AVMs Wins at National Track Championship

By Jamie McDonald, Co-Director and Genetic Counselor, University of Utah HHT Center



Connor McDonald Kamm had the usual reasons to be grateful when he won the 5000m run at the NCAA Division III Track and Field National Championship in June. After crossing the finish line FIRST, he credited superb coaching, a blessedly injury-free season to train hard and well, and a race day when the stars lined up in his favor. Not mentioned in the post-race interview was that he also has HHT and had multiple lung AVMs treated when he was 16.

Connor comes from a family that has known they have HHT for several generations. But like many families, our family didn't fully realize the extent of the condition until several family members had disabling or fatal complications. Connor's sister died before he was born of complications of a brain AVM. A cousin survived a brain hemorrhage related to a brain AVM at age 10, but not without weeks in a coma and months in rehabilitation. My aunt died at 24 years of age from a brain abscess — a complication of lung AVMs. I had a mini-stroke in my early 30s before my lung AVMs were detected and treated.



Thus, by the time Connor was born, our family had learned the wisdom of screening all those with HHT for brain and lung AVMs early in life. Since brain and lung AVMs can be fixed once found, we knew it made sense to detect and treat them prior to experiencing a complication. Our family was also involved with early HHT genetic research in the 1990s, and the result of this research indicated that Connor had inherited HHT from me. A brain MRI scan was done to rule out brain AVMs. Fortunately, no brain AVMs were detected. However, lung AVMs were

detected in this very active, healthy young man. Although they did not keep him from playing sports as a child, it was determined that the oxygen in his blood dropped significantly below normal when he exercised. In effect, the lung AVMs were limiting his exercise capacity to some extent. More significantly, leaving the lung AVMs untreated put him at increased risk for brain abscess and stroke.

So at age 16, prior to any obvious symptom from his lung AVMs, Connor was treated at the University of Utah HHT Center using the non-



surgical, coil embolization procedure. No doubt this allowed Connor to realize his potential as a runner during high school and college, culminating in his recent National Championship win. But, however proud his father and I are of his running exploits — we are even more *comforted* by the knowledge that he will proceed through life without the medical risks posed by untreated lung AVMs.

Connor graduated from Williams College in June, and will begin a job this fall teaching Spanish and coaching running and jazz band at the Montgomery Bell Academy in Nashville.

The HHT Foundation would like to congratulate Connor on his NCAA Division III National Championship and for sharing his story to help raise awareness by informing others about HHT, which will ultimately save lives! We wish him well both on and off the track.

