

THE SOUTH AFRICAN WHO MADE THE WORLD AWARE OF HAEMOCHROMATOSIS

TAGGED 'CRACKPOT' NOW CALLED 'SAINT'



Some years ago, a prominent South African researcher wrote about a book with the strange title of *“The Bronze Killer”*—in which the writer, Marie Warder, described her husband’s horrific battle with a disease far too long considered rare—that it was ‘the story of a remarkable man and an extraordinary relationship’. ... To me it is more than just about a disease!

On the Internet I saw this book recently described as the *‘definitive book about Haemochromatosis’*, and I agree. The reviewer was right—but, to me, it is more than a layman’s reference to a genetic disorder. It is a consummate love story. Love at first sight...the enduring adoration of a teenager for a young man—adoration which would lead her, in time, along a thorny path and, against all odds, to a fight against ignorance of a disease. That fight has culminated in the saving of hundreds of thousands of lives around the world.

As far as I am concerned, it is due to her heroic efforts that Haemochromatosis is now recognized as the world’s most common genetic disorder and, bearing this in mind, ever since I heard about the launch of the Cape Town branch of the Haemochromatosis Society of South Africa—in the Christiaan Barnard auditorium—earlier this year, and the society’s participation in the Genetics conference held in Somerset West, I have wondered how someone, so far away in Canada, feels about having to live through these—to her, momentous happenings—vicariously.

My thoughts go to a newspaper headline quoted by Charles Magill in his story about Marie Warder, in the *‘Reader’s Digest’*, where he wrote “As more and more physicians and researchers ‘do the talking these days, and invite me to participate out of courtesy or kindness’, Canada’s Iron Lady must surely feel vindicated.”

“Once called crackpot—now called saint...” reads the headline of an article in the “Victoria Times Colonist”—but, Magill goes on to write, “She says she can’t help wishing that Haemochromatosis had been taken seriously long ago. She cannot help ‘mourning the ones who have suffered and died unnecessarily’ in the meantime!”

Charles Magill concludes his article by quoting Dr. Malcolm Brigden: “Marie has built an international organization, and tirelessly disseminated information about the disease,” he says. “To me, she’s an authentic Canadian hero.”

To me, personally, *she is South Africa’s heroine.*

Former filmmaker, Eugene Boyko, went further. “The doctor I was going to was in a total quandary until Marie alerted us to the disease. Because of her and the treatment I have had, I have gained an extra ten or twenty years.”

And Magill, himself observes: “Hundreds, perhaps thousands, of Haemochromatosis victims who have been diagnosed or helped, thanks to Marie Warder’s tireless crusade would say ‘amen’ to that.”

“Not because of me,” she protests, shaking her head. *“With God’s help, because of Tom!”*

Elaine Murray

THE HAEMOCHROMATOSIS SOCIETY OF SOUTH AFRICA (HSSA)

In 1987 Marie was interviewed by Tony Youngusband of the Johannesburg “Star”, which led to a story in “Personality”. Shortly after that, during a prolonged stay with her brother-in-law and sister, in Kimberley, Marie addressed the National Council of Women, the “ToCH” and two chapters of Rotary, which provided her with the opportunity to launch the **Haemochromatosis Society of South Africa**. The Kimberley-based “Diamond Fields Advertiser” featured a comprehensive report on these activities, and no sooner had that appeared, than it transpired that all the other newspapers of the Argus group had picked up the “Star” article. News of the newly established society was most decidedly “out”. In 1997, Ten years later, to the day, she addressed the same National Council of Women group, in Beaconsfield.

As far as the Haemochromatosis Society of South Africa was concerned, the time that Tom and Marie Warder spent in South Africa at that time, had the promise of being extremely fruitful, and their efforts were enhanced by a number of circumstances, one of which was at the same time tragic, yet truly fortuitous. Mike McCann, a colourful, popular, and very well known journalist, was found to be suffering from Haemochromatosis only weeks before his death. So greatly was he revered and loved by his colleagues that they took turns to watch at his bedside, and it was one of them, Heidi Holland, who interviewed Marie. Her three-page story entitled “The Bronze Killer”, appeared together with a full-page colour photograph of Mike in the magazine supplement of “Sunday Times.”

It just so happened that elsewhere, in that same issue of the newspaper, there was a review of the Hemingway biography (with a mention of Haemochromatosis) as well as the prominently placed story of a woman who had undergone premature menopause in her early thirties because of Haemochromatosis. After correct intervention on the part of an astute physician, she had made medical history by becoming the first woman ever to give birth after having been so badly afflicted by iron overload. The article was made more compelling by a picture of the new mother, her husband and infant son, with a charming footnote to the effect that the baby—later to be christened Christopher—was, at the time the photograph was taken, still being referred to as “Rusty”. As a consequence, media coverage relating to the disease and the establishment of the society was excellent; so was advance publicity for Marie’s book, which tied in with several stories. Once again it was the “The Bronze Killer” reference that had captured the attention of both the press and the public.

For a while after Tom’s death, in South Africa in 1992, she wanted nothing to do with Haemochromatosis, but when in 1993 she was invited to the first World Health Organization meeting on “The Prevention and Control of Haemochromatosis”, she accepted the invitation, and was very soon back on the campaign trail once more. Now, after devoting the best part of her life to Haemochromatosis, she is back to doing what she likes best. ... Playing the piano and writing stories. ... However, although she says that she has ‘let go of Haemochromatosis’, it will not let go of her. The phone still rings, and desperate people still call or write. ...The tail still wags the dog.

In 2006, she marked the North American release of her 20th book, “Dominic Verwey—Samaritan of the Sahara”, and her ardent hope is that all her works will some day be available in South Africa, the country of her birth, and that physicians everywhere, will readily recognize the symptoms of the world’s most common genetic disorder.

“Find us one person, and we have hope of saving a family,” is the motto of the societies she has founded.

Elaine Murray

