Hypertrophic Cardiomyopathy Association (HCMA)

A Patient's Journey Living with Hypertrophic Cardiomyopathy (HCM)

Presented by Rush Roberts – HCMA Patient Advocate

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My HCM Bio

- Diagnosed at 33
- Myectomy at 36
- ICD implant at 37

My HCM symptoms improved greatly after surgery but, I started to experience arrhythmia as the scarring on my heart healed. This happens sometimes in patients after surgery.



How did HCM impact me?

- Open heart surgery (1)
- Pacemaker implant (1)
- Radiofrequency ablations (5)
- BNP: under 100 and holding



Sudden Death

One of the most comprehensive studies of sudden cardiac death in athletes was published in 2006: <u>https://pubmed.ncbi.nlm.nih.gov/19221222/</u>

- Dr. Barry Maron contributed to the study and is one of the most respected researchers in the HCM community.
- There is overlap between the two fields of study since cardiomyopathy makes up the largest share of sudden cardiac deaths in athletes.



Famous Athletes

- Hank Gathers: college basketball player for Loyola Marymount, died March 1990 (age 23)
- Reggie Lewis: NBA player for the Celtics, died 1993 (age 27)
- Gaines Adams: NFL player for the Buccaneers, died 2010 (age 26)

These are only a few that died suddenly from complications related to undiagnosed cardiomyopathy.



Impacting the Family

- My great-grandfather passed away in 1942 at the age of 48
- My grandfather passed away in 1956 at the age of 31
- HCM was formally identified by a pathologist in London in 1957
- My father was the first Roberts in three generations of our family tree to turn 49

Treatment has come a long way in 60 years!





Questions?



