

Featured Story: A Personal Message from Ben, South Africa



"...When a Barth sufferer gets sick, it doesn't only affect him but affects everyone around him too, from family to friends. By finding a cure you will not only be helping the sufferer but also his family and friends. When a Barth sufferer passes away, it is not only traumatizing for his family but also for all his friends who also suffer with Barth syndrome and their family members in the Barth syndrome community." ~ Ben, South Africa

Ben (09/02/1994 - 11/17/2010)



Jeannette & Ben