

Book

Beating hearts

I was always intensely curious as a child about the scar on my mother's chest. It traces a line from just under her collarbone about 5 inches downwards, a deep valley of scar tissue at its core. When I asked, she would smile and tell me that it was from when the hole in her heart was patched up. As I grew up, she would tell me how when she was 19 years old, the atrial septal defect was repaired by Donald Ross, the South African-born surgeon who did the UK's first heart transplantation. The operation was fairly experimental at the time, and there were no guarantees then that she would go on to live a healthy life.

Before I opened photographer Max Gerber's chronicle of children with heart disease, I had naively assumed that nearly four decades later, with the massive advances in cardiology, things would be different

for these children. I didn't expect that the paralysing fear my mother went through from not being told what was wrong with her, and the loneliness of being separated from her siblings (a sickly child, she lived with my grandparents in Ghana while her four brothers and sisters were racing

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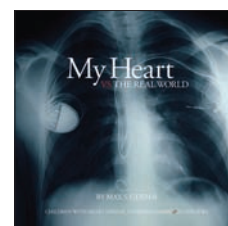
around a boarding school in India) would feature just as strongly in the lives of fairly privileged American children.

It's true that heart surgeons today can do miracles their predecessors could only have dreamt of—beating heart surgery, for example—but Gerber's anthology reminds us that

the human reactions to crisis and social differences don't change. The ten children featured in the book are courageous, determined, and optimistic. They are also acutely aware, as my mother was, of how different they are from their friends—that they can't run as fast or for as long; that they have to be careful when playing ball sports in case they get hit in the chest; and that every now and then, their childhood will be punctuated with trips to the hospital.

The patchwork quilt of images is threaded together by passages of text from the children themselves, and their parents. Although the text must have been distilled from interviews, the words read as though they have been directly transcribed with little interference from an editor. The resulting text, with all the colloquialism and haphazard narrative of everyday speech, has a much more powerful effect than the most artful prose of a professional writer. In many ways, this approach epitomises the blunt, un-sugarcoated attitude to life that the children share, and a desire to know the truth is something several of their testimonies touch on. Patty recalls only finding out about her heart condition when she overheard a doctor discuss it with her parents; the very same day, she was scheduled for surgery. "My mouth was just open; I couldn't believe what was going on," she says. What children want to be when they grow up is often a window into their world. For these children, their heart disease is so engrained in their psyche that two want to design medical devices and one wants to be a doctor.

Several of Gerber's photographs are haunting depictions of the children in their toughest moments—in immense pain just after surgery, for example. But because Gerber has shared the children's experiences—he



My Heart vs the Real World: Children with Heart Disease, In Photographs & Interviews
Max S Gerber. Cold Spring Harbor Laboratory Press, 2008.
Pp 203. US\$29.00.
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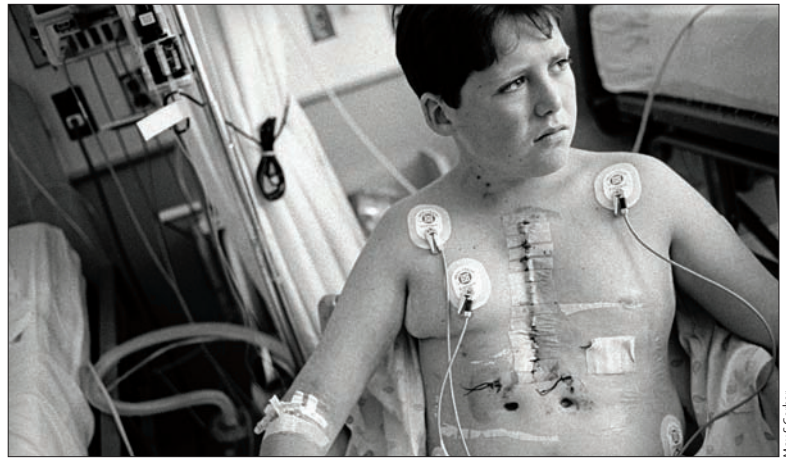


Max S Gerber

Micah Bangert-Burroughs who has tetralogy of Fallot with pulmonary atresia

was born with bradycardia and has a pacemaker—the photographs feel intimate rather than voyeuristic.

The way Gerber manages to convey a complex whirl of emotions and qualities, such as determination, vulnerability, and sorrow, in a single frame is partly due to this shared intimacy with his subjects, but it is also down to his innate skill for portraiture. The portraits Gerber has snapped over the past decades range from top scientists like James Watson to Hollywood actors like Carrie Fisher, but all the images capture that often-elusive connection between photographer and subject. His modest explanation belies Gerber's immense gift: "People who are uncomfortable having their picture taken are somehow comfortable with me."



Scott Antolick after valve replacement

Perhaps, as Gerber says, children who suffer these sort of challenges enter adulthood with a profound maturity, cutting through life's nonsense to get "right to the chase". "We've got an

unfair advantage", he says, "we've got a heart like a motor".

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