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Tetralogy of Fallot Foundation, USA

Long term effects and the congenital gap

Within congenital medicine, heart patients suffering from Congenital Heart Defects (Specifically referencing Tetralogy of Fallot patients in our presentation) There is a universal medical system disconnect within medical care (either preventative, emergency or routine treatment) which operates with a large hole underlying systematic patient care which compromises patient safety. The effects of this gap range from small complications during treatment to the worst outcome being the death of a patient. The lack of continuing education for General Cardiologists, the miniscule number of properly trained and certified Adult Congenital Doctors, the undersized fields of Adult Congenital Medicine and the current practices of using a Pediatric Cardiologist teamed with a General Cardiologist to try and properly treat an Adult Congenital Heart Patient (Tetralogy of Fallot Specific) has shown to help but, the data contrary to the success of these combined efforts shows the need for a serious overhaul and restructuring of present and future medical practices. Medical mandates proposing continuing education and a greater awareness needed by doctors treating such CHD/TOF patients to avoid such preventable negative occurrences are needed, detrimental to the overall health and longevity of a CHD patient and the data that is recorded shows mild complications, to progressive complications during treatment or, ultimately the death of the patient. Jay Risk, a CHD/TOF patient is speaking about his own experiences, research through his foundation and his views are non-bias. According to the US National Library of Medicine, “47% of patients are successful when transferring from pediatric to adult congenital medicine. Thus, 53% of overall patients experience mild to serious complications, even death. 53% is more than half of the CHD patient population, warranting a new and serious focus and stronger efforts being concentrated in solutions.

Biography

Jay Risk is the National Spokesman for the Tetralogy of Fallot Foundation Inc., a non-profit organization focused on growing the fields of Adult Congenital Medicine, bridging the congenital gap, giving the condition a voice, providing a national institution for patients and families suffering from TOF and building a National TOF Network for awareness. He is also a Comedian, Producer, Technical Director and has appeared on the soap opera 'The Guiding Light', the TLC Channel, 'People Are Talking' with Matt Lauer from 'The Today Show', Regis and Kathy Lee, ABC pilot 'Florida's Last Call' performed at the IMPROV Comedy Clubs, recently worked with Renee Taylor from the sitcom 'The Nanny' and just filmed a commercial with Judy Gold from TrueTV and Rosie O'Donnell from the 'Rosie O'Donnell Show'.

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