

Invited Commentary

Involvement of patients and parents in research generated by the Australian and New Zealand Fontan Registry

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THE CONTRIBUTION FROM D'UDEKEM ET AL,¹ Melbourne, Australia is the latest in a series of important papers from the same group regarding the outcome of the Fontan operation, as documented in the Australia New Zealand Fontan Registry. The concepts presented here might seem foreign to some, but will be enthusiastically embraced by most of us working in the paediatric cardiac specialties. The authors have presented their strategies to capitalise on our most precious assets, namely our patients and their families, in research that may be of direct benefit to both groups. At the same time, patients and families are empowered and encouraged to take some control of their future. Knowing not only what to expect, but also how such predictions can be scientifically formulated, will improve both quality of life and satisfaction. As noted by the authors, there may be important

questions that are worth addressing, but which are known only to those living with a Fontan circulation. The strategies outlined have already brought some of these issues to the forefront. As such, the Australia New Zealand strategy outlined goes well beyond the conventional patient support group initiatives. We would expect that this strategy will soon be widely accepted, and will become the expected model for future research within the paediatric cardiac domain. Congratulations to the authors for their groundbreaking contribution.

Reference

1. d'Udekem Y, Forsdick V, du Plessis K. Involvement of patients and parents in research generated by the Australian and New Zealand Fontan Registry. *Cardiol Young* 2017; 10.1017/S1047951117001494.