

An International Fontan Registry

- **OBJECTIVES.**

- Build up population based data of size and outcomes of this population
- Elucidate the causes and mechanisms of death
- Follow the time-course and impact of liver disease
- Build up a scoring of the health of the Fontan circulation
- Build up the tool that will facilitate recruitment for research projects
- Build up cohorts of patients.
- Study regional variation – improve care

An International Fontan Registry

- **DESIGN.**
- One overarching Registry with very limited dataset
- Sub-registries with comprehensive data
 - Death and transplantation
 - Liver outcomes
 - Risk scoring
- High linkage capacity

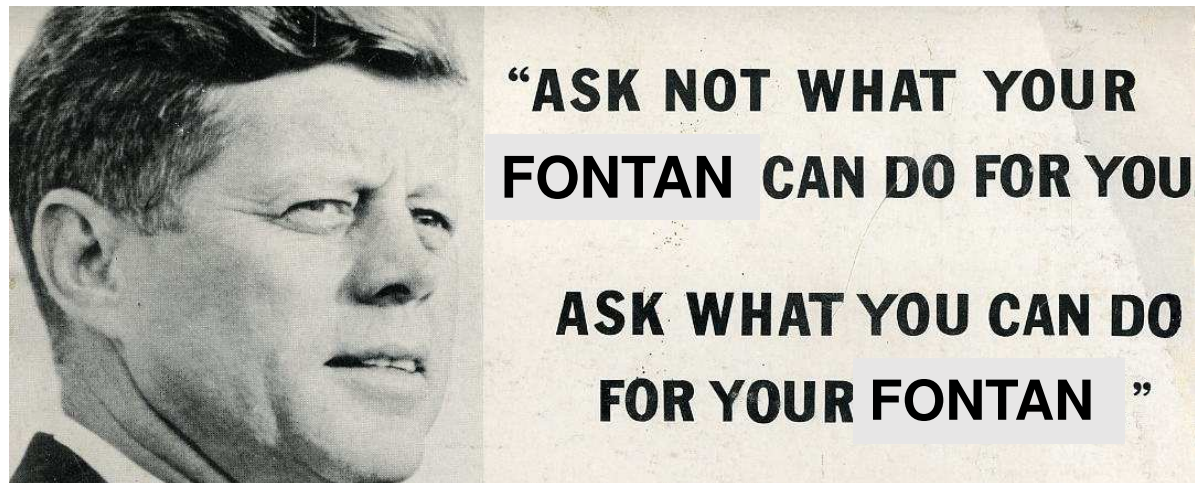


Dr Ajay Iyengar



Dr Michael Daley

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