Women’s health

2 research consensus panels

- March 2005: Uterine Artery Embolization (UAE) Fibroid Registry for Outcomes Data (FIBROID) Registry, and then to the development of the Uterine Fibroid Symptom Health-Related Quality of Life Questionnaire (UFS-QOL).
- Oct. 2017: Pelvic Venous Disorders (PeVD)

- Led to FSDG funding, the establishment of the Uterine Artery Embolization (UAE) Fibroid Registry for Outcomes Data (FIBROID) Registry, and then to the development of the Uterine Fibroid Symptom Health-Related Quality of Life Questionnaire (UFS-QOL).
- Led to a FSDG grant and the creation of an International Pelvic Venous Work Group (IPVWG) that is developing a tool for patient-reported outcomes (PRO) related to PeVD treatment.

11 grants funded

- 6 Pilot Research
- 2 Other
- 1 Dr. Ernest J. Ring Academic Development
- 1 Academic Transition

continued
UAE FIBROID Registry

- **Uterine Artery Embolization (UAE) Fibroid Registry for Outcomes Data (FIBROID) Registry**
  - was established in 2002 to collect data on the safety and effectiveness of UAE for the treatment of fibroids. It also assessed the procedure's impact on fertility and quality-of-life, including giving them the option of a shorter recovery period.

- This registry has allowed IRs to directly market to women. With strong data supporting the safety, efficacy and legitimacy of the procedure, IRs are able to make inroads that help women learn about options, giving them more control over their personal choice of therapy. The study enrolled more than 3,000 women across 72 sites for UAE treatment.

- The FIBROID registry was funded by SIR Foundation and SIR, in cooperation with the Duke Clinical Research Institute (DCRI).

- **Uterine Fibroid Symptom Health-Related Quality of Life Questionnaire (UFS-QOL)** is a self-reported patient questionnaire used to measure both a patient's objective pre-treatment and post-treatment symptoms (e.g., bleeding, cramping) and subjective experiences (e.g., a patient feeling “blue” or “less productive”). The responses may indicate the severity of the patient's condition without more invasive measures and could subsequently aid in determining treatment.

- The UFS-QOL is available for use in research studies in a variety of translations. A copy of the questionnaire can be requested at https://www.sirfoundation.org/clinical-research2/clinical-research/ufs-qol/

- The questionnaire was developed through a grant provided by SIR Foundation in conjunction with the RAND Corporation.