



# Endometriosis Association

## 35-Year Impact Statement

The Endometriosis Association was the first organization in the world dedicated to endometriosis – giving a voice to women, girls, and families affected by the disease.

### A Proud Legacy of Firsts:

#### **RESEARCH & TRANSLATIONAL MEDICINE**

- First to establish an endometriosis research registry, largest in the world for 2 decades
- First to show that endometriosis is a disease of all socioeconomic groups, pre-teen to post-menopausal women, and of all racial groups
- First to establish ongoing multi-disciplinary research programs
- **First to lead the field of science and medicine in the big picture of endometriosis:**
  - documented long delay between onset of symptoms and diagnosis
  - demonstrated that pain, not infertility, is the cardinal symptom of endo
  - shifted focus from “just” a pelvic disease to a systemic one
  - showed a link to atopic diseases
  - discovered higher rate of autoimmune diseases
  - linked to certain cancers
  - linked to gut dysbiosis and immunotherapy
  - discovered and proved a cause of endo and its link to epigenetics
  - discovered dioxin link in endo pathophysiology, first proven agent to be able to cause spontaneous, severe endo
  - showed disease is chronic, now accepted and promulgated in medical society guidelines
  - groundbreaking research on non-invasive diagnostics

#### **EDUCATION & FUNDRAISING**

- First to develop extensive lay literature on endo, available in 31 languages
- First to publish four books on endo, one in Spanish
- Contributed numerous chapters to medical textbooks and journals
- Raised more than \$8 million direct dollars for endo research
- Instrumental in helping raise more than \$21 million indirect dollars for research

#### **SUPPORT**

- First to organize support groups and develop national organizations worldwide; had members and groups in 66 countries and over 200 support groups in the U.S. and Canada alone
- First to create a global network of highly-motivated individuals touched by endo (women, families, physicians, medical researchers)