Communicating with Key Stakeholders to Develop a National Research Agenda for Food Allergy

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January 31 2019
Patient Centered Outcomes Research Institute (PCORI) Award

Effective May 1, 2016 for two year term

Goal was to bring patient voice to the prioritization of food allergy research

Conducted open RFP for members
• 5 x number of applicants received
Comprised of 44 key stakeholders including:
- Patients
- Caregivers
- School Nurses
- Clinicians
- Research Scientists
- Insurance Companies/PBM
- Food Allergy Advocates

Organized into four Regional Boards:
- Midwest
- Northeast Mid-Atlantic
- South
- West
ORAB Process

- Facilitated by FARE staff members and KOLs
- Monthly National Board conference calls
- Quarterly Regional Board meetings
- Regional Boards drafted white papers to identify 5-6 regional research priorities. After facilitated discussion, developed national research priorities
- ORAB members presented priorities to KOL research scientists, FDA, NIH, and pharmaceutical representatives at FARE Research Retreat April 2017
2017 ORAB Research Priorities

- Therapeutic Developments
  - Preventive/curative
  - Treatment of reactions

- Diagnostic Processes
  - Improved accuracy
  - Improved safety and ease of testing

- Improved Product Labeling

- Quality of Life Issues
Year Two ORAB Focus – Psychosocial and Dissemination of Findings

- The Psychosocial Impact of Clinical Trials
- Psychosocial Research Needs
- Clinical Needs for Center of Excellence Sites
- Broad dissemination and implementation of findings
Clinical Needs for Center of Excellence Sites

- Importance of assessing food allergy-related psychosocial concerns *early* – before they develop
  - development and dissemination of validated screeners for psychosocial concerns

- Education of allergy medical providers on warning signs that warrant further treatment and evaluation
  - training of allergy immunology providers during training and on-going certification
2 peer reviewed scientific journal publications; 1 in final review; 1 in draft
4 non peer review publications (popular media)
15 presentations (made or accepted at)
• 6 major academic conferences
• 7 professional conferences
• 2 lay conferences
6 Abstracts/Posters presented at scientific conferences, 1 submitted
Ongoing engagement with stakeholders
• Education and Advocacy
• Patient Registry
• Survey of FCN Sites
• Opening Panel FARE Research Retreat April 2019