RareLaunch: Research Ready

“Impact of Research When Your Organization Drives It”
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Patient Organization Involvement in Research

**Why**

- Better health outcomes
- Improve doctor-patient relationships
- Research informs standard of care
- Leverage the patient voice
- Creates disease awareness

**How**

- Develop a research culture in your organization
- Identify research priorities
- Educate/communicate to your community
- Lead and design research projects
- Share results and data
Develop a Research Culture in Your Organization

What is a Research Culture

• Your organization’s attitudes, values and expectations towards research
• Encompasses the behaviors of you, your team, and your patient community
• It influences researchers' career paths and determines the way that research is conducted and communicated
• Developing a research culture takes time and careful maintenance
Identify Research Priorities

• Establish a group of medical advisors
  • Find KOL’s – researchers, clinicians, take multidisciplinary approach
  • Identify gaps in research
• Create a patient advisory council
  • Ask key questions about health research priorities/outcomes
  • Allow patient to lead - committee chairs or co-investigators
• Engage research organizations like: NIH, academies and associations
  • Meet with leadership
  • Hold meetings or symposia
Educate/Communicate to Your Community

- Community engagement is the link between basic and clinical research
- Educate patients on how to get involved and self-advocate
- Determine knowledge gaps
- Address relevant clinical questions
- Survey your community frequently
- Address patient burdens
- Provide access to research opportunities
- Connect patients and researchers
Lead and Design Research Projects

- Start a registry or natural history study
- Facilitate focus groups for researchers
- Fund a clinical scholarship – young investigators or a student
- Small seed grants – basic research or pilot studies
- Hold scientific meetings or symposia
- Publish - utilize medical students or researchers to include your name
- Establish a biobank to collect samples
- Work with drug developers on clinical trial design and enrollment
Share Results and Data

• Collect, collect, collect - the more data you have the better
• Establish agreements and guidelines on how the data will be shared
• Accelerates drug development in disease space
• Creates disease recognition and awareness
• Illustrates the power of the patient voice
• Leads to improved therapies patient outcomes
Harness the Power of Research to Drive Your Organization!