

RELA FINDINGS: Many Shared Priorities & Challenges

PRIORITIES

CHALLENGES

Information & Support

Connecting patient to patient
Connecting patient to specialist
Diagnosing patients early & accurately

Delivering services to disparate patients
Providing specialized support across broad spectrum
Lack of professional collaboration

Research

Funding translational science
Developing Natural History Registries
Understanding the Mechanism of Disease

Connecting researchers to seed collaborations
Access to funding
Acquiring sufficient patient data for clinical trials

Professional Education

Educating professionals to detect & diagnose diseases
Developing & disseminating best clinical practices
Updating researcher thinking on Rare conditions

Educating disparate professionals
Treating small numbers of patients
Unwillingness to learn beyond scope of practice focus

Advocacy

Connecting with every patient diagnosed
Raising disease awareness
Expediting collaborative registries, biomarkers, clinical trials

Lack of public awareness
Short on time, money and trained staff
Rapid growth of diseases

Fundraising

Developing major donor strategies
Developing fundraising strategies
Cultivating donors

Families in crisis/survival mode
Soliciting donations from nonimpacted persons
Lack of skilled development experts