Hydrocephalus Association Research Initiative

October 26, 2012
Our Mission

To eliminate the challenges of hydrocephalus.
Long Term Goals

1) Support and educate individuals, families and professionals dealing with the complex issues of this condition

2) Drive the hydrocephalus research agenda by directly funding $3MM annually and influencing government granting entities to ensure that hydrocephalus is provided its “fair share” of research support
Critical Research Problems

- Inadequate resources devoted to hydrocephalus
- Complexity of hydrocephalus makes it difficult to treat, to understand, to attack scientifically, and to forge a comprehensive research and fundraising agenda
- Causes and mechanisms are poorly understood and in many cases unknown
- Diverse, fractionated, scattered research activities
- Clinical practice variations, quality, and patient safety
- Shunts are unacceptably problematic
Research Initiative

- Address critical research problems
- Lead with Mentored Young Investigators
- Develop research plan with advisors
- Seek $3 million to fund plan
- Garner support from major donors
HA Research Priorities

1. Stimulate research ecosystem
2. Improve clinical outcomes and QOL
3. Advance study of etiologies

- CSF regulation
- Genetics
- Bio-Markers
- Bio/Pharma interventions
- Tissue Banks, Shared Animal Models
- Shunt Infection
- Shunt Failure
- Cog/Behav Assessment
- Practice Variation
- Registry
- Clinical Research Network
- Career Development (MYI, Mid Career, Visiting Professors)

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HA Research Conference

Bench and Translational  Clinical
Grants to seven Mentored Young Investigators ($770K)
Two awardees for CSF dynamics grant ($400K)
Partnership with HCRN
  • Sustain Hydrocephalus Clinical Research Network
  • Initiate parallel adult lines of research
Research conference in Seattle, July 2012
Planning $1M RFA in CSF regulation and biomarkers
Launched $3M “Reason for Hope” campaign
Raised $1,900,000 toward goal
10 new researchers committed to hydrocephalus

Significant gains in treatments
  - Protocol to reduce infection rates by 40%
  - Increase life of shunt before failure
  - Evidence based standardization of treatments

Identify previously unknown targets for therapeutics

Increased annual NIH spending