



The Business of Creating Hope – With You September 20, 2014

Alone we can do so little; together we can do so much – Helen Keller

ECD Global Alliance

Supporting Those Affected by Erdheim-Chester Disease



Hope Beyond Borders





Hope = Research



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Mission:

- Advocate for and support research programs
- Raise awareness of ECD
- Provide support to all affected by ECD
- Share educational material and facilitate information sharing

Never doubt that a small group of thoughtful, committed, citizens can change the world. Indeed, it is the only thing that ever has.” — Margaret Mead



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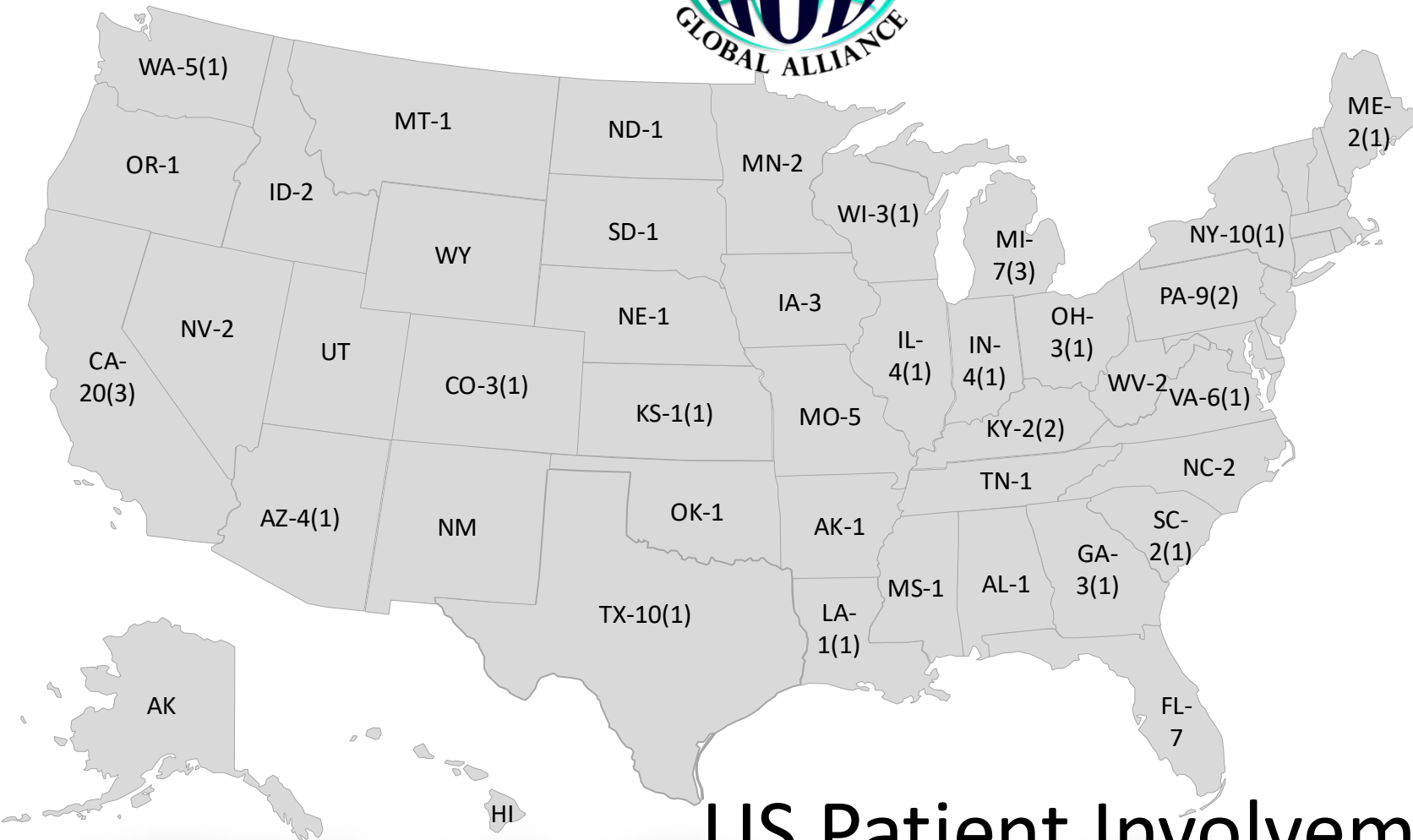
Hope = Research

Research = Patients + Money



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- VT
- NH
- MA-4(1)
- RI
- CT-1
- NJ-3(1)
- DE-1
- DC
- MD-3
- HI-1
- PR-1
- Unkn-3(1)

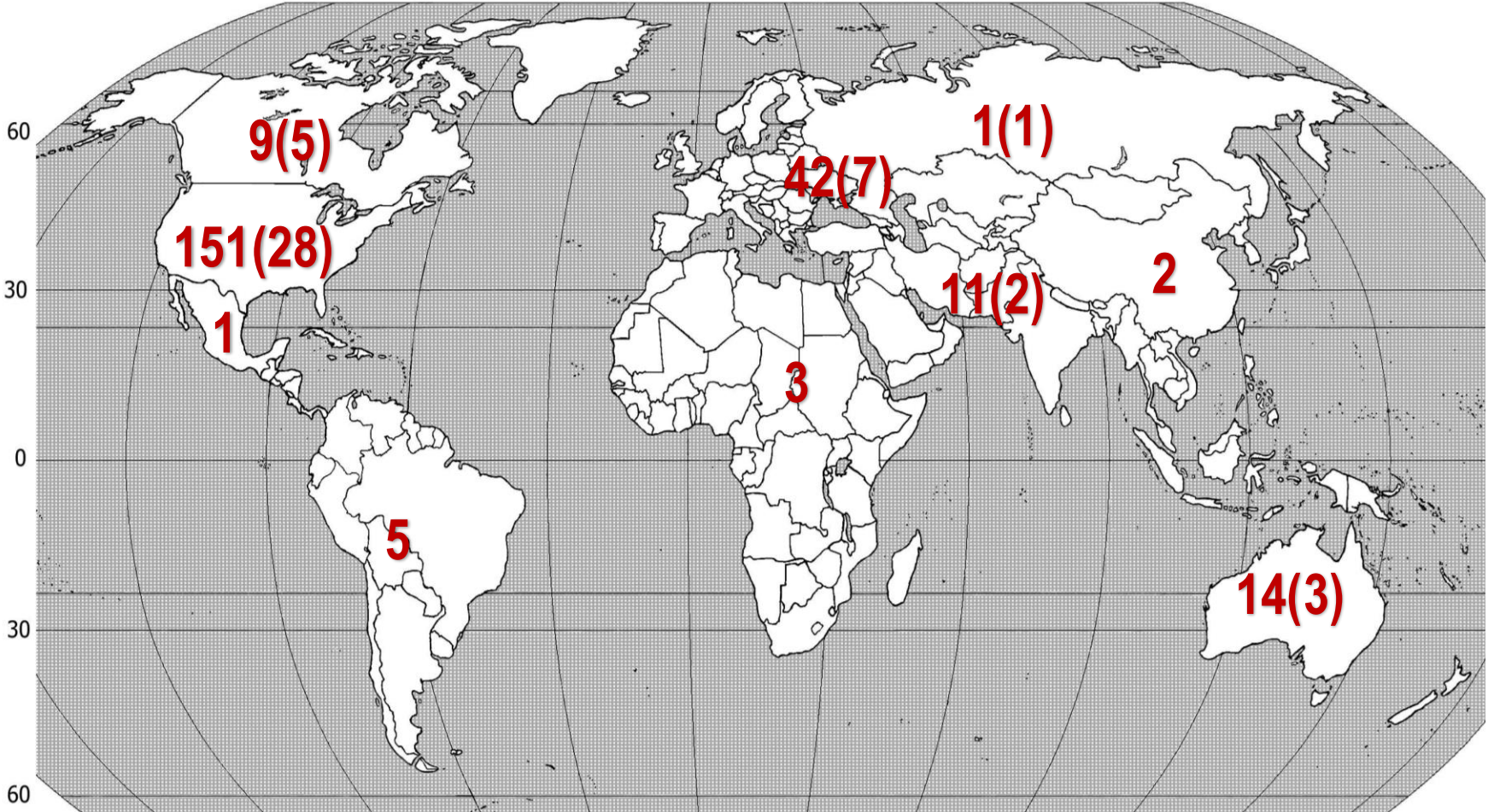
US Patient Involvement

State - # patients registered(# deceased patients)

It is about the individuals.

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World Patient Involvement

patients registered(# deceased patients)

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Donations (Thank YOU!)

- Communities
- Patients
- Families
- Friends
- Working on Corporate



Although fundraising is NOT the focus,
it is required to carry out the mission.





Research = Patients + Money



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World Research Involvement

US



- Texas Children's
- MD Anderson
- NIH
- Sloan-Kettering
- Others beginning

Europe

- Paris, France
- Milan, Italy
- Parma, Italy
- Leeds, England



Asia

- Tel Aviv, Israel



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ECD Research: 2nd Annual ECD Medical Symposium

Countries Represented: Canada, France, Italy, Sweden, Israel, Australia, England, US

US Institutions Represented:

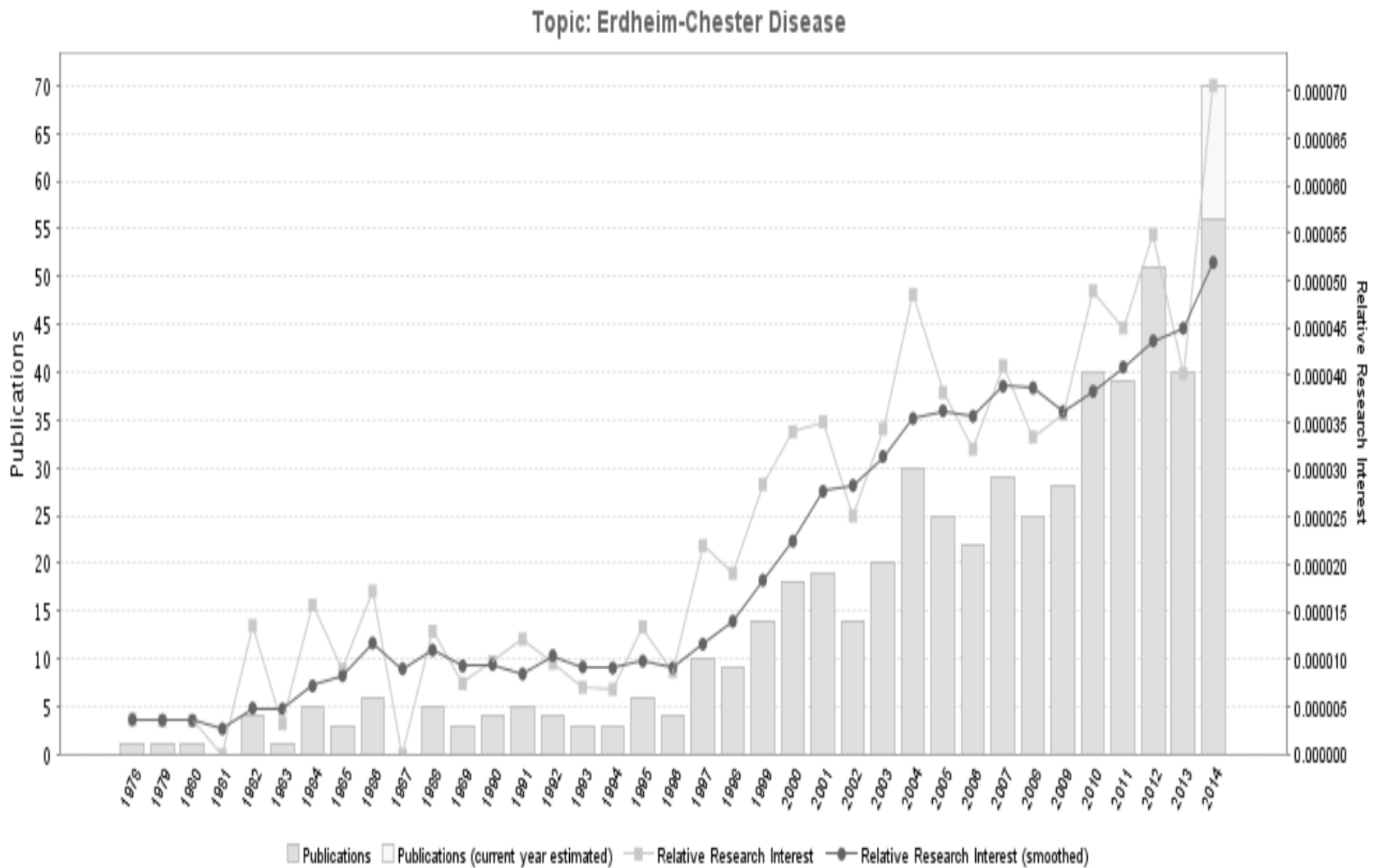
Johns Hopkins, Mayo, MD Anderson, NIH, Sloan-Kettering, Texas Children's, Univ. Florida, etc.



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of Publications





Research = Patients + Money



= HOPE



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ECD Global Alliance Accomplishments

- Research Grants Provided - \$150,000
- Medical Symposia – 2012, 2013, 2014
- Patient and Family Gatherings – 2013, 2014
- Largest Group of ECD Patients in the World, Makes Possible Research
- Community Support Available

Goals

1. Fund Research
2. Provide Support
3. Raise Awareness



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Positive Changes in the ECD World Resulting from the ECD-GA Work

- Growing Awareness
- More People Being Correctly Diagnosed
- Consensus Guidelines Published on Diagnosis and Treatment of ECD
- ECD Studies & Trials Available
- Research Occurring and Growing
- Clinical Treatment Centers Being Identified
- Community Available for Sharing and Support
- More Effective Treatments Available



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ECD Global Alliance

Near Future

- Research Grants
- 2015 International Medical Symposium
- 2015 Patient and Family Gathering
- Centers of Care
- Patient Registry
- New Website
- More Languages
- Advocating with Insurance Companies



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ECD-GA Team

✓ Board of Directors (uncompensated)

- 6 Members
(Rachel, Glenn, Pam, Linda, Dr. E-V, Kathy)

✓ Staff

- 2 part-time members
(Crissy, Jessi)

✓ Other Volunteers (uncompensated)

- Simon, Bengt, Brad, DawnMarie, Vivian, Aisling, Nick, Bridget, John, Randy, Medical Community, Sonia, Susie, Blaine, Maria, Julie, Dearbhaile, Karla, Alice, Mike, Lee, Eugenia, RuthAnn, Cindy, etc.





Projected 2014-2015 Expenditures

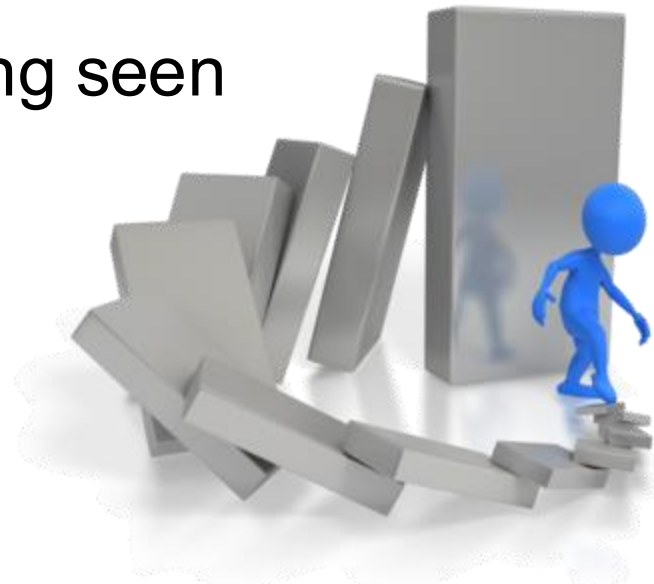
- Research Grants (\$150,000 - \$320,000)
- Symposium and Patient & Family Gathering (\$75,000 x 2)
- Website Development (\$10,000)
- Travel (\$10,000)
- Translations (\$2,000-\$15,000)
- Operational Expenses & Salaries (\$60,000 x 2)





Success Brings Challenges

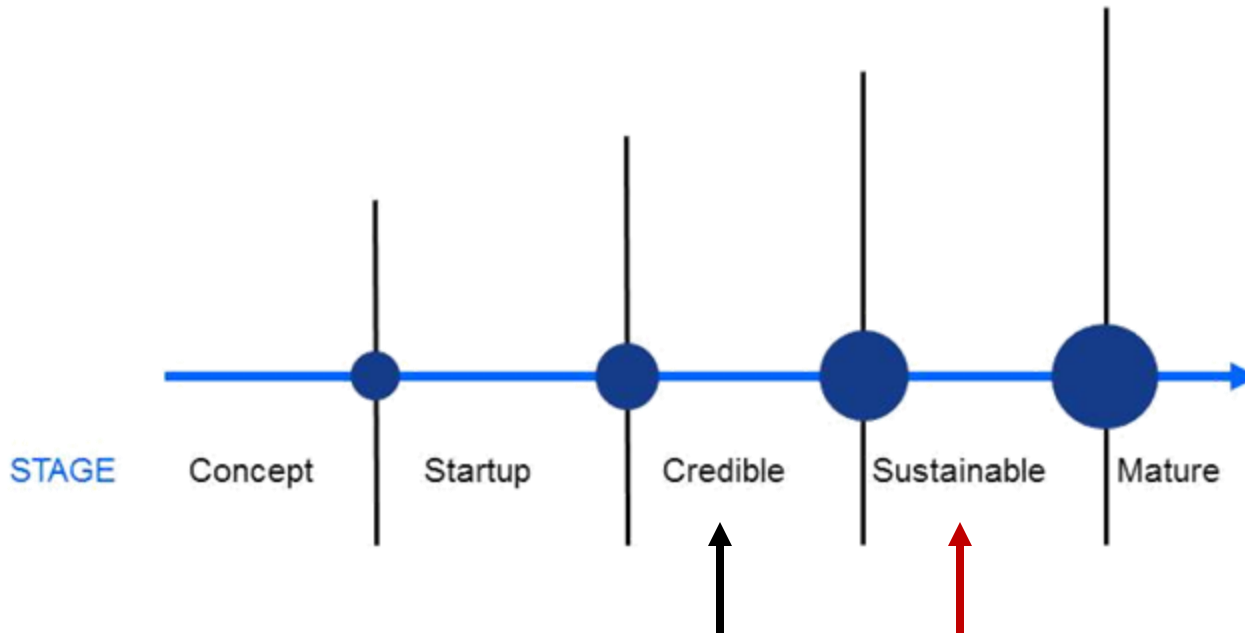
- ✓ Began as kitchen table, start-up organization
- ✓ Grew into a recognized patient advocacy group
- ✓ Impacts of organization now being seen
- ✓ Help is needed to maintain the momentum
- ✓ More involvement & donors are needed to sustain activity





Organization Maturity

Five Stages of Evolution



We need your help to move from here to here.



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Current Needs

- ✓ Active and Committed Board Members
- ✓ Fundraisers
- ✓ Special Skills
 - Insurance Company Processes
 - Public Relations
 - Medical System Workings
 - Social Media
 - Legal
 - Grant Writing and/or administration





***You must be the change you want
to see in the world.***

- Mahatma Gandhi



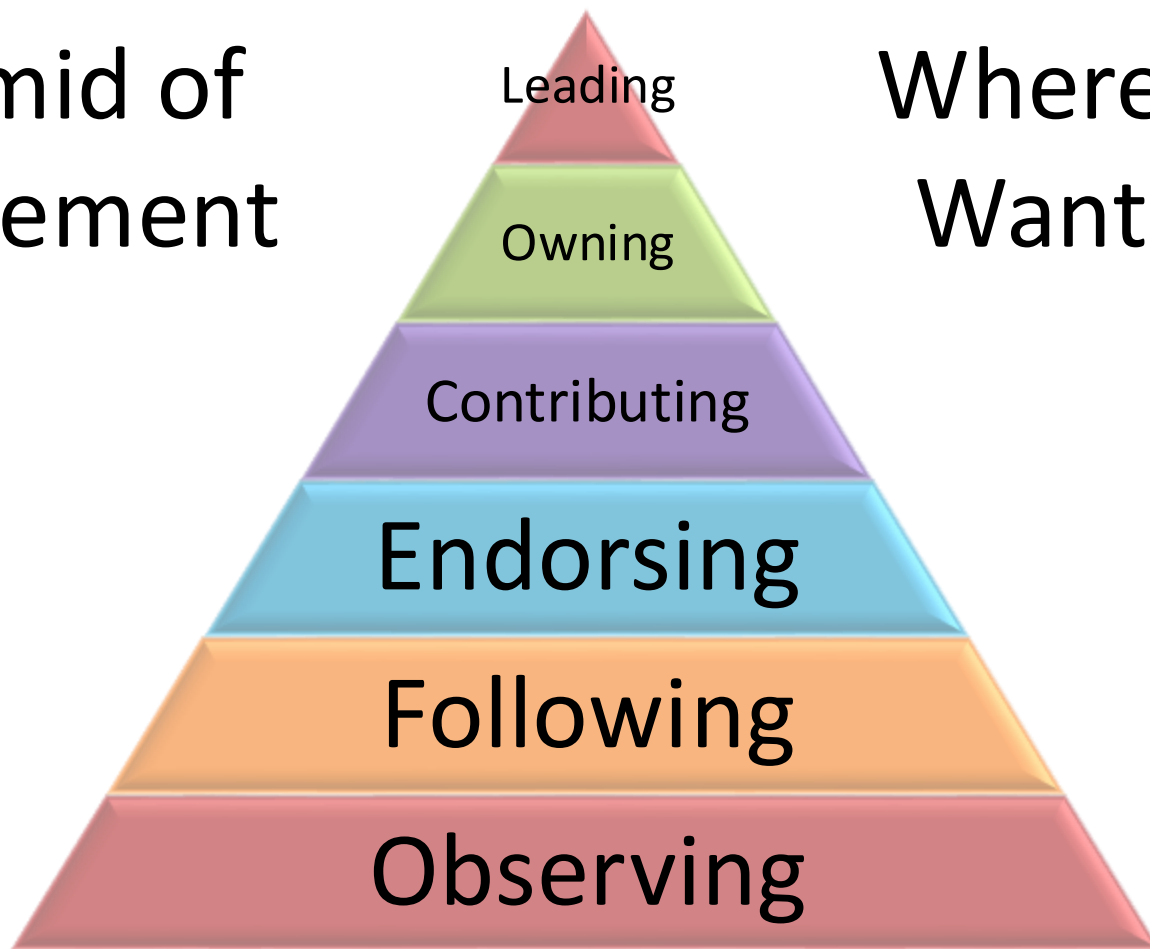
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Pyramid of
Engagement

Where do You
Want to Be?



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How Can WE Sustain What has Begun?

It Will Take Us Working Together.

- ✓ Your Questions?
- ✓ Your Ideas?
- ✓ Your Commitments?



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Questions?

Thank you



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