Power of Patient Groups

Do It For Yourself, Do It For Others

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“Alone we can do so little, together we can do so much.”

Helen Keller
The Tyrosinema Story

Getting By With The Help of Friends (and Family)

- Recognizing something had to be done
- Resources were out there, how to access them
- Mobilizing family and friends
- Making a significant impact
“Coming together is a beginning; keeping together is progress; working together is success.” - Henry Ford
Snapshots of Rare Disease Patient Advocacy Groups Successes

- Filling a Void
- Resolving Inequities
- Raising Awareness
- Equalizing the Odds
- Encouraging Research/Drug Development
- Providing hope for a future
“Growth is never by mere chance; it is the result of forces working together. “

James Cash Penney
Growth of ECD-GA

Working on a wing, prayer, shoestring and determination

- Within 7 years, has achieved more than most rare disease support groups
- Serendipitous moments have led to interesting conversations and opportunities
- Individuals ‘on a mission’
- Not afraid to ask for advice or even directions!
- Yet can’t do this alone... all hands on deck!
“I know there is strength in the differences between us. I know there is comfort, where we overlap.” –Ani DiFranco
“Are You Talking to Me?”
-Robert DeNiro

- Each took different road to ECD-GA.
- Everyone has her/his own story to share.
- May not always agree with one another.
- May find untapped abilities.
- Working toward a common goal.
- We invite you to participate however you can.
- We can learn from each other.
Some things to think about:

- Tell or share your story
- Serve on a committee
- Participate in studies and/or registry
- Matching gifts/workplace campaigns
- Instead of gifts…
- Lend a talented hand
- Host an Event
- Participate in studies and/or registry
“Nobody's going to fix the world for us, but working together, making use of technological innovations and human communities alike, we might just be able to fix it ourselves.” - Jamais Cascio
Looking Towards the Future

- Potential treatments being developed
  - Consider clinical trial
  - Keep informed on what is happening
  - Discuss with your physician

- ECD Registry
  - Way to entice researchers to study ECD
  - Your input is vital to create a natural history
  - Provides valuable information on this rare disease
“Never doubt that a small group of thoughtful, committed people can change the world: indeed it’s the only thing that ever has!”

-Margaret Meade
Thank You!