

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



“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!