

How Does Our Association Grow?

International Alliance of ALS/MND Associations Presentation for the 18th Annual Meeting Jane H. Gilbert, President & CEO The ALS Association December 8, 2010

Growing Pains and Solutions

The seeds were planted 25 years ago...



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Growing Pains and Solutions

- The Association is in it's 25th year
 - Two groups came together
 - New York and California
 - Other groups were invited to join as well
- Growth has been extraordinary
 - 41 Chapters
 - 34 Certified Centers
 - National Organization coordinating activity
- Three Major branches of The Association
 - Research—World Class program
 - Care Giving—including our Chapters and Center
 - Advocacy—only program of its kind in the United States



After 25 Years Change Was Needed





After 25 Years Change Was Needed

- Why?
 - Non profit climate has changed
 - Donors are more sophisticated
 - Giving in the United States is down
 - Economy in the United States in flux
- Other ALS organizations have grown
 - While The Association continues to do great work, so do other ALS groups
 - Recognized the need to partner
 - Recognized the need to use dollars wisely
 - Recognized we need to play to our strengths and our assets
- The Association wanted to grow to meet increased needs
 - What path to take?



The First Steps





The First Steps

- Followed the path suggested by a study conducted by Booz Allen Hamilton
 - Governance
 - Fundraising
 - Communications
 - Technology
- First effort was governance—led to the obvious
- The ALS Association needed to Change!
 - New way of doing business



- Took the pulse of the organization including all stakeholders
- Looked at our strengths
 - Chapters
 - Center and Clinic Relationships
 - Donors
- Started down the path of Change
 - Never easy
 - Tough decisions
 - Careful consideration of consequences





What We Did

- Trimmed National Staff
- Cut the Operating Budget
- Looked to our Chapter Network for collaborative projects
- Revised our Governance Structure with emphasis on the Chapters
- Moved our headquarters to Washington DC
- Working smarter and not harder
- Reaching out to potential partners





The Early Results

- Research funding is up with requests for proposals out
- Advocacy is front and center with the delivery of the new ALS Registry
- Care Giving is a major focus
 - Transformation group is working to determine how we can best serve people living with the disease, their families and circle of care givers
 - Centers will receive an increase in funding
 - Center and Research will work together for best results
- Budget for next year is increased by over 2 ml dollars



Continued

- Development Initiatives are working
 - Chapters are participating in a national Direct Marketing program
 - Our Walk to Defeat has a new major market focus
 - New Planned Giving program for Chapters
 - The Promise Fund is ready to launch
 - We're starting a new radiothon in major markets
- Goal
 - A growth rate of over 15 million additional dollars over the next 5 years





The End Game



- We are a stronger Association
- We raise more money
- We are able to meet our mission:
 - Research, Care Giving, Advocacy

We create a world without ALS!!!