

# Meeting Patient and Family Needs Across the Lifespan: Psychological and Social Support Programs

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# Tuberous Sclerosis Complex (TSC)

- **Nephew, Clint, diagnosed with TSC at 3 months of age in 1985**
- **Told he would not live to be 5**
- **Little known about the disease, no research, no answers**
- **TS Alliance gave us information and hope**



# Tuberous Sclerosis Complex (TSC)



- **Son, Andy, diagnosed with TSC at 8 months of age**
- **Diagnosed after receiving his diagnosis**
- **Our needs and challenges were very different then, and are very different now**

# Patient and Family Needs

- **What are the needs?**
  - Emotional support
  - Information about the disease
  - Access to health care professionals
  - Information about research on the disease and access to studies, clinical trials, patient registries, etc.

# Patient and Family Needs

- **The needs change over time**
  - **Different needs for newly diagnosed child and their parents versus needs of individual diagnosed as an adult**
  - **Different over the lifespan**
    - **Manifestations in childhood**
      - **Health, education, social development**
    - **Needs and challenges of adolescents**
    - **Issues for adults**

# Psychosocial and Social Support Programs

- **Communication**
  - Listservs, chat rooms, e-mail
  - Web sites, blogs, Webinars
  - Newsletters
- **Educational meetings and conferences**
- **Social networking**
- **Fund raising events**

# Tuberous Sclerosis International

- Consortium of organizations for individuals with Tuberous Sclerosis Complex (TSC) and their families
- Meetings at international conferences
- Share information, brochures, materials
- Collaborate on research projects
- Develop consensus guidelines, diagnostic criteria together
- Assist with health care professional education
- Provide information and support to individuals with TSC, their families, health care professionals, educators and employers

# TSC Global Research

- **Identification of the TSC1 and TSC2 genes**
- **Development of molecular diagnostic testing**
- **Development of multidisciplinary TSC Clinics – USA, UK, Germany, Italy, France (Canada coming soon!)**
- **TSC1/2 Variation Database**
  - Catalogue all variations
- **TSC Natural History Database**
  - Information about individuals with TSC over their lifespan (birth to death)
- **International TSC Clinical Consortium**



# Beyond TSC...

- **Partner with other organizations**
  - LAM Treatment Alliance, LAM Foundation, PKD Foundation, CURE,
  - Join organizations like NORD, Genetic Alliance, National Health Council, Research America, National Coalition for Health Professional Education in Genetics
- **Professional societies**
  - American Epilepsy Society, American Thoracic Society, Child Neurology Society, American Academy of Neurology, and others

# It Takes a Village

- **“We can do so much more by working together than each of us could ever do on our own.”**

