

Soaring on the Wings of Hope



2017 AHC FAMILY GATHERING

Cure AHC Strategic Plan

Jeff Wuchich, Co-Founder & President

MAIN COMPONENTS

- Research/Quality of Life Improvement
- Awareness/Operations
- Fundraising

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RESEARCH/QUALITY OF LIFE

- **Duke University**
 - **Mouse Models (ATP1A3 & ATP1A2)**
 - **Functional Studies**
 - **Treatment trials of existing compounds**
 - **AHC Multidisciplinary Clinic**
 - **Clinical Research Coordinator**
 - **Financial/Logistical Support for Families to Attend**
 - **Continued development of Symptom management approaches**
 - **Strategic investigation of structure of novel therapeutic compound**

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RESEARCH/QUALITY OF LIFE

- Columbia University
 - Optogenetics studies
 - Understand molecular consequences of ATP1A3 (and ATP1A2 Mutations)
 - Screen for candidate compounds for treatment/cure
 - Search for Root Cause of Non- ATP1A3/2 AHC Cases

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RESEARCH/QUALITY OF LIFE

- Aarhus University (Denmark)
 - Neuroelectrophysiological Study
 - Follow –on to Previously Published research
 - May shed light on the viability/possibility of exome skipping/gene editing approaches
 - Awarded \$33,000 US 7/2017

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RESEARCH/QUALITY OF LIFE

• IAHCRC

- Cloud Platform (\$6,000 given in 2017)
 - Platform to house and analyze comprehensive
- AHC-OBSERV (\$23,000 given in 2017)
 - Natural history study of AHC
 - Data collection through Duke/Columbia
- AHC Research Fellowship
 - Identify expertise gaps
 - Attract qualified researchers to fill gaps
- Annual Research Symposium

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AWARENESS/OPERATIONAL

- Awareness
 - Advocacy to Government Entities
 - Rare Disease Week
 - In District Lobby Days
 - Empowering families globally to interact with their governments
 - Google Grants
 - Expand landing pages/ConnectAd program
 - Telling your Story Locally
 - Developing a template process for engaging local media regarding your AHC Champion and the efforts Cure AHC is undertaking to get to the cure
 - Social Media Expansion
 - Attending Medical Conferences (Child Neurology, Pediatrics, etc.)
 - Chief Aims
 - Find undiagnosed cases
 - Feed into Operational/Fundraising

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AWARENESS/OPERATIONAL

- Operational
 - Volunteer Program
 - Identify Needs/Time commitments
 - Skills Assessment
 - Matching needs & Skills
 - Board of Directors
 - Actively recruiting additional member with Strong Fundraising Ability/Network (have enlarged our roster by 4)
 - Term limits
 - Officer development
 - Development/Parent Advisory Council
 - Defined expectations
 - Self/Peer evaluation vs. expectations
 - Website
 - Reorganize content for ease of access
 - Increase content for more value to families, caregivers, supporters, and donors
 - Refresh/redesign Biannually to keep fresh and current
 - Business Plan
 - Case Statement
 - Promotional Materials

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FUNDRAISING

- **Goal - \$2,000,000 in 2 years**
 - **Major Donor Funnel Expansion**
 - Community awareness efforts
 - Board of Directors Spheres of influence
 - Profiling of high net worth individuals and foundations with affinity
 - target 10 prospects per source and backfill as converted/opted out
 - Leverage Awareness/Operational Assets to achieve
 - **Grass Roots Events**
 - Roll out templates for variety of fundraising events with clear definitions of time commitments
 - Virtual events
 - Auctions
 - Active events (running, cycling)
 - **Grants**
 - Target corporations and private foundations
 - Potential to form “chapters” of Cure AHC to pursue more localized grants
 - Explore international grants and foundations
 - Work with BioPontis Alliance
 - **Membership**
 - Incentives for supporters to step up financially
 - Will NEVER exclude any AHC family from receiving help from Cure AHC
 - Levels and perks TBA

CALL TO ACTION

- Draw Inspiration from Disease even Rarer than AHC
 - Giant Axonal Neuropathy (GAN)
 - Only 30 known cases
 - \$7,000,000 raised in 10 years
 - Phase 3 clinical trial
 - target 10 prospects per source and backfill as converted/opted out
 - Leverage Awareness/Operational Assets to achieve
- Abundance Mentality
 - Someone in your network/community has
 - The time to be involved
 - The connections to help us achieve our goals
 - The heart to help
 - No amount is "too small"
 - The momentum is REAL
 - Research is advancing rapidly
 - Our tremendous successes will breed even more success

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CureAHC

Alternating Hemiplegia of Childhood

www.cureahc.org