

## **American Brain Coalition Strategic Plan**

### **I. Mission**

The American Brain Coalition, a non-profit organization, seeks to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through public advocacy.

### **II. Vision**

The ABC will be a strong and powerful voice for people with disabling brain disorders bringing together organizations that represent concerned and interested patients, families, and professionals. This voice will be used to advocate for increased support of research that will lead to better treatment; services and support that will improve patients' quality of life; as well as a national commitment towards finding cures for individuals with disabling neurological and psychiatric disorders.

### **III. Organization History and Profile**

In March 2000, the One Voice Neurological Coalition was launched by the American Academy of Neurology (AAN) and over 50 professional and patient organizations. The One Voice coalition has evolved into the American Brain Coalition (ABC) to encompass a broader membership. The intentions of One Voice were to bring together representatives of patient advocacy organizations, physician organizations, and other related groups that focus on the prevention, study, treatment, and cure of brain and neurological diseases and disorders. Leveraging the combined resources of member organizations can improve the quality of life for all people affected by brain and nervous system diseases and disorders. Moreover, creating a dialogue between patients and providers that focuses on patient needs across diseases can lead to changes in the training and education of health care providers, legislation in support of chronic care needs, and improved treatment for patients.

Further meetings helped the coalition refine its mission, vision, and goals. Coalition members determined that broadening its scope to include neurosurgeons, psychiatric professionals, and mental health organizations would be more inclusive and present greater advocacy opportunities. With the assistance of the Society for Neuroscience (SfN), the organization renamed itself the American Brain Coalition in April, 2004 and incorporated as a non-profit group.

The ABC is a coalition made up of three organizing members – the American Academy of Neurology, the Society for Neuroscience, and the American College of Neuropsychopharmacology – as well as 47 diverse organizations and advocacy groups drawn from patients, researchers, and clinicians.

### **IV. Critical Issues and Strategic Priorities**

Strategy formulation is a combination of rational, scientific examinations and educated, intuitive best guesses. The ABC's strategy formulation is determined by the recent membership survey results, as well as Board discussions. The process entails:

- examining the organization's critical issues and strategic priorities
- determining how the organization's strengths and skills can be employed to address the critical issues
- analyzing opportunities and strengths and looking for ways to synthesize the two
- exploring and choosing the best approaches for the organization.

## **A. Legislative Strategy**

### **Strategic Priority:**

The challenges and the opportunities facing biomedical research are unparalleled. In this post budget-doubling era for the National Institutes of Health, much of Congress is not convinced that strong funding is still needed. Yet the explosion of new knowledge holds great promise for treatment of brain diseases and justifies additional funding support.

It is important for the ABC to advocate on behalf of those with debilitating brain disorders. The ABC's main legislative priorities will remain increasing funding for biomedical research at the NIH, supporting animals in research, supporting mental health parity legislation, improving health care for chronic conditions particular to the brain, and eliminating restrictions on federally funded stem cell research.

### **Goals and Objectives:**

Continue providing regular updates to the ABC members on research and legislation.

Continue advocating to Congress for funding for biomedical research at the National Institutes of Health (NIH), for mental health parity—insurance coverage for treating mental illness should be the same as for physical illness, for supporting animals in research, for seeking to improve the healthcare system to better serve people with chronic illnesses affecting brain and mental health, and for eliminating restrictions on federally funded stem cell research.

Encourage our members to utilize Capwiz, ABC's legislative software program.

### **Action Plan:**

ABC staff be keyed in to all legislative affairs on the Hill and inform members as soon as a key issue arises.

Increase the number of letters sent to the Hill. This might include endorsement and/or disapproval of specific legislation, thank you letters, congratulations letters, or general policy statements. Post all correspondence on the ABC website.

The ABC Advocacy Committee will continue reviewing the key legislative priorities to ensure they represent the entire membership.

ABC Staff will work with ABC members for face-to-face meetings with their legislators or their staff.

Increase the number of legislative alerts sent to the ABC member organizations. Post these alerts on the ABC's website.

Continue to submit written testimony when applicable.

Look into a live chat and/or forum to educate patients on the importance of ABC advocacy, and the simplicity of the legislative software program.

## **B. Data Collection Strategy**

### **Strategic Priority:**

Exploring and compiling data on the impact of brain disease in the U.S. will provide the ABC and its members with a compelling snapshot of the economic burden of brain disease – data that will support our collective and individual advocacy efforts for increasing federal funding for biomedical research directed to the understanding and solving neurological conditions.

### **Goals and Objectives:**

To obtain comprehensive data on the economic, medical, and social impact of brain disease in the U.S. to share with Congress and the public.

### **Action Plan:**

Designate an individual from most member organizations to help craft a concrete goals and objectives proposal to pitch to the government or industry for financial support in obtaining the data.

## **C. ABC Own Entity Strategy – COMPLETED IN FEBRUARY 2008**

### **Strategic Priority:**

Two of ABC's organizing members currently provide professional support for the ABC. Breaking away from the umbrella of these two organizations will allow the ABC to become more independent. Many organizations and advocacy groups have been hesitant about joining the ABC, as they see the ABC as captives of these two large organizations. If the ABC were to become its own entity, there wouldn't be the perception that these organizations are influencing the decision-making process.

### **Goals and Objectives:**

The ABC to become its own entity and break away from the umbrella of the current organizations by January 2008.

### **Action Plan:**

The ABC Director will work with the Chair and Board in developing a Business Plan outlining what needs to happen for the ABC to become an independent organization by January 2008. The Business Plan will include administrative support from outside vendors.

## **D. Member Recruitment Strategy**

### **Strategic Priority:**

Bringing together representatives of patient advocacy organizations, along with scientific research and physician organizations, as well as other related groups that focus on the prevention, study, treatment, and cure of brain and neurological diseases and disorders, help create a powerful voice to further advocate on behalf of debilitating brain disorders. Leveraging the combined resources of member organizations can improve the quality of life for all people affected by brain and nervous system diseases and disorders.

### **Goals and Objectives:**

ABC hopes to achieve the same level of public awareness and support for diseases of the brain that have been realized by the American Heart Association for heart disease and the American Cancer Society for cancer. Only when the public understands how 50 million of their relatives, friends, and neighbors are affected by diseases of the brain and mental illness will we attract the level of support for research and care needed to prevent, control, and cure these diseases.

### **Action Plan:**

Develop an ABC Membership Committee tasked with determining goals for increasing ABC's membership, to include outreach by all ABC members.

## **E. Member Retention Strategy**

### **Strategic Priority:**

Each of the patient and medical communities has been engaged in advocacy and public awareness in their separate spheres with good success. The ABC needs to utilize the strength of its members by solidifying the overall ABC message.

Ensuring ABC's member expectations are met by providing them with kind of support they need is important to ABC's overall success.

### **Goals and Objectives:**

Enhance ABC's member satisfaction and networking opportunities.

### **Action Plan:**

Create a Strategic Planning Group who will meet via conference call monthly to discuss the varying issues facing the ABC membership.

Task the ABC Strategic Planning Group with reviewing the list of non-legislative issues the membership would like to see addressed.

Begin an ABC newsletter to be distributed to members and affiliates. Members can highlight important events going on in their organization.

Create opportunities to have more time to exchange information (network) during meetings.

## **F. Public Education and Outreach Strategy**

### **Strategic Priority:**

The public has insufficient awareness of the mass numbers of individuals in our society afflicted by disorders of the brain, as well as the importance of financial support for research.

### **Goals and Objectives:**

Disseminate information to the public on brain disorders, the important of research, and the importance of collecting economic data.

### **Action Plan:**

Produce documents to help the lay audience understand the importance of research.

Outreach during Brain Awareness Week, National Movement Disorders Awareness Month, and other brain related days.

Increase involvement of ABC members in public education and outreach.