

Letter to the Sponsors, Donors and Supporters of Autism Speaks

Category : Changing Perceptions of Autism and Disability

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The following letter from over 60 disability rights organizations has been sent to numerous national sponsors of Autism Speaks. Individual signatories can show their support by signing the petition at <http://www.ipetitions.com/petition/AutismSpeaks>. Please feel free to distribute this to your networks.

To the Sponsors, Donors and Supporters of Autism Speaks:

We, the undersigned organizations representing self advocates, parents, professionals and allies in the Autism, Autistic and Disability Communities, are writing to you to express our concern about the recent actions of Autism Speaks. Our work is about helping empower and support people with disabilities of all kinds, including adults and youth on the autism spectrum, and we recognize that there are a wide variety of means towards accomplishing this goal. Yet, Autism Speaks' recent choice to use fear, stigma, misinformation and prejudice against Autistic people as a fundraising tool does real damage to people with disabilities everywhere. The most recent example of this lack of ethics can be found in Autism Speaks' new "I am Autism" campaign which states, *"I am autism...I know where you live...I work faster than pediatric AIDS, cancer and diabetes combined. And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands and I will bankrupt you for my own self-gain...I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain...I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness."*

Not only does this campaign rely on offensive stereotypes and inaccurate information (research indicates that parents of Autistic children are not more likely to divorce than parents of non-Autistic children), but it also does real damage to the cause of disability rights. By choosing to portray Autistic people as husks of real people, stolen out of our own bodies, Autism Speaks reinforces stereotypes and prejudice against people with disabilities that have existed for centuries and have been the source of pain, segregation and violence.

We are calling on you to end your support for Autism Speaks and to find new ways to show your support for Autistic people and others with disabilities. As the result of a pattern of unethical behavior and irresponsible governance, outlined below, we believe that Autism Speaks as an organization no longer deserves your time, energy, money and support.

Autism Speaks uses damaging and offensive fundraising tactics which rely on fear, stereotypes and devaluing the lives of people on the autism spectrum: Autism Speaks' unethical fundraising tactics are not limited to the new "I am Autism" video. Its television Public Service Announcements compare having a child on the autism spectrum to having a child caught in a fatal car accident or struck by lightning. In fact, the idea of autism as a fate worse than death is a frequent theme in their fundraising and awareness efforts, going back to their "Autism Every Day" film in 2005. Indeed, throughout Autism Speaks' fundraising is a consistent and unfortunate theme of fear, pity and prejudice, presenting Autistic adults and children not as full human beings but as

burdens on society that must be eliminated as soon as possible.

Very little money donated to Autism Speaks goes toward helping Autistic people and families:

According to their 2008 annual report, only 4% of Autism Speaks' budget goes towards the "Family Service" grants that are the organization's means of funding services. Given the huge sums of money Autism Speaks raises from local communities as compared to the miniscule sums it gives back, it is not an exaggeration to say that Autism Speaks is a tremendous drain on the ability of communities to fund autism service-provision and education initiatives. Furthermore, while the bulk of Autism Speaks' budget (65%) goes toward genetic and biomedical research, only a small minority of Autism Speaks' research budget goes towards research oriented around improving services, supports, treatments and educational methodologies, with most funding going towards basic research oriented around causation and genetic research, including the prospect of prenatal testing. Although Autism Speaks has not prioritized services with a practical impact for families and individuals in its budget, its rates of executive pay are the highest in the autism world, with annual salaries as high as \$600,000 a year.

Autism Speaks excludes the people it pretends to represent: Autism Speaks is one of an increasingly few number of major disability advocacy organizations that refuse to include any individual with the disability they purport to serve on their board of directors or at any point in their leadership and decision-making processes. In large part due to Autism Speaks' public relations strategy of presenting Autistic people as silent burdens on society rather than human beings with thoughts, feelings and opinions, Autism Speaks' governance policies are deeply unrepresentative and out of step with the mainstream of the disability non-profit community.

Contrary to the "I am Autism" video, which equates autism with AIDS and Cancer, autism is not a terminal disease. It is a disability, one that comes with significant challenges in a wide variety of realms. Yet the answer to those challenges is not to create a world in which people are afraid of people on the autism spectrum. The answer is not to create a world in which the word autism is met with terror, hatred and prejudice. It is to work to create a society that recognizes the civil rights of Autistic people and others with disabilities. It is to work to create a world in which people with disabilities can benefit from the supports, the services and the educational tools necessary to empower them to be full citizens in society.

We are Autism's true voice – Autistic people and those with other disabilities ourselves, and our allies, family members, friends and supporters. Autism Speaks does not speak for us. We are not stolen – we are right here. Our lives may be difficult – but they are worth living. Autism Speaks Does Not Speak For Us and we will not work with an organization that relies on damaging and offensive stereotypes to advance an agenda out of step with those they purport to represent. We call upon you to recognize this and find better avenues for your admirable desire to support Autistic people and our families. We call upon you to end your support for Autism Speaks.

National and International Organizations:

The Autistic Self Advocacy Network

Self-Advocates Becoming Empowered (SABE)

The National Council on Independent Living (NCIL)

ADAPT

TASH

The Arc of the United States

Disability Rights and Education Defense Fund (DREDF)

The National Youth Leadership Network (NYLN)

Autism Network International (ANI)

The Autism National Committee

Little People of America (LPA)

Not Dead Yet

The Bazelon Center for Mental Health Law

National Coalition for Disability Rights/ADA Watch

The Autistic Spectrum Partnership In Research and Education (AASPIRE)

Mothers From Hell 2

The Center for Self-Determination

Disability Rights Advocates

Kids As Self-Advocates (KASA)

Service Dog Central

MHONA International

The National Empowerment Center

Disabled Youth Collective (DYP)

The National Coalition of Mental Health Consumer/Survivor Organizations

Feminist Response in Disability Activism (FRIDA)

The ICORS Asperger's Listserv

International:

Autistic Self-Advocacy Network-Australia

Autism Rights Group Highland (in Scotland, United Kingdom)

The Autistic Community of Israel

Autreach IT in the United Kingdom

The Southwest Autistic Rights Movement (SWARM) in the United Kingdom

The London Autistic Rights Movement (LARM)

The Aspergers Network in the United Kingdom

Local, State, and Regional Organizations:

ADAPT-Montana

The Center for Disability Rights in Rochester, NY

The Regional Center for Independent Living in Rochester, NY

The Michigan Disability Rights Coalition

The Institute for Disability Access in Austin, Texas

The Maryland Coalition for Inclusive Education

The Paraquad Center for Independent Living in St. Louis, Missouri

The Lonesome Doves in Pennsylvania

TASH-New England

Together Enhancing Autism Awareness in Mississippi (TEAAM)

Wesleyan Students for Disability Rights at Wesleyan University in Connecticut

Tangram in Indianapolis, Indiana

The Disability Activists Work Group (DAWG) in Oregon

APSE-Oklahoma

North Carolina Disability Action Network

Access Living of Metropolitan Chicago in Chicago, Illinois

Topeka Independent Living Resource Center in Topeka, Kansas

Disabilityworks in Chicago, Illinois

Ardinger Consultants & Associates in Maryland

Statewide Parent Advocacy Network of New Jersey

Wisconsin Family Assistance Center for Education, Training and Support

Aspergers Young Adults of North Alabama (AYANA)

Access to Independence of Cortland County, Cortland, New York

Youth Power, New York

The New York Association on Independent Living

Self-Advocates As Leaders (SAAL) in Oregon

Green Country Independent Living Resource Center

Elementary Inclusive Education Program at Teachers College, Columbia University

Beyond Compliance Coordinating Committee at Syracuse University

Green Mountain Self-Advocates in Vermont

Advance Youth Leadership Power in Chicago, Illinois

Organizations that signed onto the letter after its initial release:

Mental Health Association of Northwestern Pennsylvania

Depression and Bipolar Support Alliance Pennsylvania

Mental-Health-Advocate.US

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