



CLUSTERBUSTERS

Finding relief from cluster headache
through research, education,
advocacy, and support.

Prospectus Annual Report — 2017



Clusterbusters® is an IRS-approved 501 (c) (3) non-profit research and educational organization dedicated to researching treatments that show promise for reliable, effective and long term relief from cluster and related headaches.

www.clusterbusters.org

Overview

Clusterbusters came to life in 2002 as an organization determined to advance research into cluster headaches and to support the cluster headache community through advocacy and awareness.

The community was in desperate need of recognition and help in finding new and improved treatment options. Our first published study made the news in 2006 in the prestigious and well respected medical journal Neurology.

This published work not only got the medical community listening but also was instrumental in finally getting the news media to start doing stories about cluster headaches. This one journal article was very important in shedding light and opening discussions on a condition that for hundreds of years had been hidden and essentially ignored.

Arising from these humble beginnings, Clusterbusters has become a community of advocates that has accomplished a great many things in helping advance the treatments available and the visibility of the cluster headache community. Clusterbusters has become one of the largest and most successful patient organizations within the headache disorder spectrum.

Our non-profit 501 (c) 3 status, coupled with all our board of directors, officers, committee members and advocates working completely on a volunteer basis, allows us to direct all donations and funding toward our research, advocating and awareness programs.

The Community

In recent years there has been an unprecedented surge in research regarding cluster headaches and the medical community actively searching for new and improved treatments. This is directly due to the unrelenting pressure put on the medical establishment by the cluster headache community. A community that sat in darkness for years demanded to be recognized and involved in improving available treatments and searching for new, safer options.

Medical Advisory Board

This review and advisory board includes some of the finest headache specialists and health professionals in the country.

We greatly appreciate these board member's input in our educational, advocacy, awareness and research endeavors and their assistance in helping make Clusterbusters a leading and trusted voice within the patient, medical and governmental administration communities.

Working Relationships

- Harvard Medical School**
 Our Case Series and research study, completed at Harvard, showed the effectiveness of treating cluster headaches with psychedelics. The results were published in the prestigious peer-reviewed medical journal Neurology and publicized cluster headaches, the need for new treatments and the possibilities that further psychedelic research might provide.
- Hannover Medical School, Hannover Germany**
 Our work with Harvard lead to a combined effort between researchers at Harvard and the Hannover Medical School, investigating the effectiveness of the non-hallucinogenic compound BOL-148 (Bromo-LSD) for cluster headaches.
- McGill University & Headache Cooperative of New England**
- University of West Georgia**
 Dr. Larry Schor
 Study of psychological and personal burden & Pain Assessment
- Yale University & Veterans Administration**



News Media

One of our most successful missions over the years has been our desire to reach the public with information on cluster headaches as well as the need for better treatments. Many people affiliated with Clusterbusters have agreed to be interviewed for news articles and TV appearances.

Our treatments and cluster headaches have been the focus of two television shows (House) as well as two different feature documentaries with National Geographic. Besides hundreds of feature stories within the web, we have reached worldwide audiences with newspapers, magazines and medical journals.

Education

Our goals in education are to not only educate sufferers about their condition and how best to deal with the condition, but also the general population, medical profession and government agencies.

Annual Conferences 2006-Present

Each year Clusterbusters holds an international conference, bringing together patients, their families and members of the medical profession. We offer presentations by the leading headache specialists and highlight all groundbreaking research.

Our attendance has grown each year and is the largest gathering of the cluster headache community in North America.

Patient Registry

Clusterbusters has built the largest cluster headache patient registry. The registry helps keep patients updated on all new research and clinical trials that are available for participation. This registry has become extremely valuable in the research process and lets research institutions know that even though clusters are rare, there are plenty of patients available to fill clinical studies.



Research: Concluded & Published

Our work has been published in the Medical Journals, Cephalgia, Neurology and The Lancet, among others.

- **Psilocybin in the treatment of cluster headaches**
Harvard University
Published in Neurology in 2006
- **Medication use and effectiveness study**
Yale & Dr. Emmanuelle Schindler
Includes work on the efficacy and safety of high flow oxygen for cluster headaches. Journal publication in 2015
- **BOL-148**
Clusterbusters work with psilocybin at Harvard lead to the discovery of an analog known as BOL-148 as an effective treatment and we funded a clinical study in Germany with the help of Hannover Medical school and a dedicated research team
- **Kudzu**
Clusterbusters funded this study and helped with all aspects including data collection and writing the protocols for a clinical study of Kudzu for treating cluster headaches. This work was done at Yale University and included the help of the Veterans Administration.
- **LSA (lysergic acid amide)**
Study again conducted at Yale/VA, Clusterbusters funded a study on LSA (a natural occurring alkaloid) and its effectiveness for treating cluster headaches.

Research: Involvement in current clinical work in process

- Genetics
- CGRP
- Personal Burden & Demographics study:
- Psilocybin & Chronic Cluster Headache
- Post Traumatic Stress Disorder

Advocacy & Awareness

Advocating for cluster headache sufferers includes diversifying along many routes as there are many areas that require improvement. The following are a few of the past and present issues we have been involved in working directly with the agencies involved in finding solutions.

- Alliance for Headache Disorders Advocacy (AHDA)
- Headache on the Hill 2012-2017
- Social Security Administration
- CMS Division SSA
- Medicare/Oxygen:
- SAMSHA - The administrators of the National Suicide Hotline.
- FDA - Bob Wold & Clusterbusters have testified before the FDA and special committees on different therapies brought in front of the agency for approval.

Affiliations

- American headache Society (AHS)
- National Headache Foundation (NHF)
- American Headache & Migraine Association (AHMA)
- Will Erwin Headache Research Center - Houston, ,Tx.
- American Headache Disorders Advocacy Organization (AHDA) - Organization Member
- National Organization for Rare Diseases (NORD) - Organization Member
- The Headache and Migrane Policy Forum
- US Pain Foundation

Providing Online Support

Social Media

Our Facebook pages reach out into the world of social media to offer a place for people to come together to talk about the issues and find others with which to share experiences.

Message Board

Our message board, linked from the website, is a more private site where people can speak about clusters, treatments and keep up with all that is taking place in the cluster community. Meet others with clusters, discuss options and solicit opinions on everything from treatments to all aspects of living a full life with cluster headaches.

Website

This website is a depository of the latest information on past and current research as well as updating people on the latest projects in which Clusterbusters is involved.

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