

Get in Step with the ALS Association

*A public relations plan to improve participation in the Walks
to D'Feet ALS in the spring of 2004*



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I. RESEARCH

❖ Client / Organization

The ALS Association is the only not-for-profit voluntary health organization dedicated solely to the fight against Amyotrophic Lateral Sclerosis, ALS, often called Lou Gehrig's disease. The mission of the ALS Association, ALSA, is to find a cure for the disease as well as improve the quality of life of the affected.

Among the organization's main goals and activities are:

- 1) to encourage, identify, fund and monitor basic scientific research directed at identifying the cause of ALS as well as a possible cure and means to prevent it,
- 2) to be the vital link for patients and their families, as well as a source for information, counseling, physician referrals, in-home visits, respite care and guidance in disease management; to deliver ALSA programs of support and services for ALS patients, their families and caregivers at a local level,
- 3) to heighten awareness of the nature of the disease and the efforts of ALSA in order to stimulate volunteerism, scientific and health care community activism, including the public support essential to fight against ALS, and
- 4) to increase awareness of ALS and ALSA in all levels of government in an effort to expand government support for research and elicit programs, as to make treatments and care accessible and affordable for all ALS patients.

The importance of ALSA's purpose can be seen through the seriousness of the disease. ALS affects more than 5,000 people in the United States every year by attacking nerve cells in the brain and spinal cord. The life expectancy after diagnosis is between two and five years. It has also been estimated that as many as 30,000 people may have the disease at any given time. However, most of the cases are not reported or are misdiagnosed as similar diseases like Parkinson's disease or multiple sclerosis. Specifically in the Carolinas, the estimate is of an existing 1,100 patients.

As one of 38 ALS Association chapters across the country, the Jim "Catfish" Hunter Chapter serves people with ALS, and their families, throughout the Carolinas. This chapter was inducted in 1987 but it has only been known as the Jim "Catfish"

Hunter Chapter since 2002. The “Catfish” Chapter is named after the famous baseball player, known both for his pitching career and batting ability, who died from ALS in 1999. Before his death, Hunter and his wife founded the Jim “Catfish” Hunter ALS Foundation in Hertford, N.C. to promote research that could lead to a cure for ALS.

The “Catfish” chapter is now located in Raleigh, NC, from where it serves both North and South Carolina. The chapter’s employees include Ashley Hurdle, who directs public relations; Mandy Parker, who is in charge of patient support and is also the chapter coordinator; Megan Gardner, who manages chapter development and is the Walk to D’Feet ALS coordinator and Jerry Dawson, who directs patient services.

Some of the services provided by the Jim “Catfish” Hunter Chapter include respite care, transportation for ALS patients who are wheelchair dependent and home visits. It also organizes support groups where patients have the opportunity to learn how others in the same situation cope and live with ALS, and also a loan closet that provides durable medical equipment such as wheelchairs, walkers, canes, hospital beds, etc.

The ALSA’s income is based on donations from private and corporate sponsors who may or may not have had experiences with ALS, funds gathered from Walks to D’Feet ALS and gala events. The Walk to D’Feet ALS is a national event sponsored by the ALSA to promote public awareness about ALS and raise funds for research and local patient and family service programs.

As ALS is not yet of common knowledge, the ALSA’s reputation is limited to those who are directly affected by the disease. However, ALSA is the largest private source of funding for ALS-exclusive research in the world.

There has been little time for proactive public relations because of the limited number of employees and the large region covered by this chapter. In an effort to increase awareness for ALS, the Carolinas Chapter was renamed in 2002 as the Jim “Catfish” Hunter Chapter, which is now the name for its official recognition. The public relations director is currently working on the development of a new chapter website and a promotional DVD explaining ALS and the organization’s mission.

In terms of strengths for an ALS public relations campaign, the ALSA benefits from not having to dispel any incorrect or unfavorable preconceived notions. As we mentioned before, the fact that ALS is not a known disease makes it is easier to shape

new opinions on it. On the other hand, the weakness that the campaign must consider is the lack of importance given to the disease. The 5,000 new cases every year has difficulty comparing itself with well-known diseases like cancer, and the fact that there is no known cure for ALS, makes it complicated to attract sponsors. Therefore, certain publics may see it as less of a threat, making it less likely that they will contribute time, effort or money to the organization.

Our public relations campaign for The ALSA will focus on the promotion of the 2004 spring Walks to D'Feet ALS. The budget for this campaign is \$25,000 for the four to five walks that will be held. The locations for the walks are Hertford, Greenville, Winston-Salem, Emerald Isle, Raleigh, Charleston, Spartanburg, Charlotte and Wilmington. However, for our purposes, this campaign will focus only on the walks in Raleigh.

In terms of funds, the 2000 walks raised \$200,014 in six cities; in 2001, they raised \$274,104 in eight cities; and in 2002 they raised \$161,694 in five cities. Most people who participated in the walks have been personally affected by the disease or have family members or friends with ALS. Committee members, who take on various aspects of the planning and fundraising, organize the walks.

❖ *Opportunity / Problem*

Our campaign is not reacting to a specific situation or problem, but proactively working toward the goal of publicizing information about the disease in general, and most specifically of promoting the Walks to D'Feet ALS. Our focus for the organization is external media relations. This approach follows the press agency/publicity model of public relations.

Our public relations plan is based on the short-range goal of improving participation in the spring walks for 2004. However, the tactics and strategies we develop can be used to promote future walks and will also work toward the ALSA's long-range goal of spreading the word about ALS and establishing a good reputation for the chapter.

Our campaign goal is to increase the amount of money raised at each individual spring walk by \$25,000 – \$50,000 in 2004. This money will be important in funding patient services, which is the most important aspect of the organization due to the short life expectancy (two to five years) of patients after diagnosis. These services cost \$125,000 to \$150,000 per year.

The rationale for the campaign goal is to better serve ALS patients by increasing the amount of funds available for research, patient services and public awareness education. Our goal will also allow residents of North and South Carolina to gain an understanding of the program and its worth in the lives of the patients it serves.

The targeted audiences for this campaign are patients, patients' loved ones, physicians, caregivers, the Raleigh student community and the news media (as an intervening public). The key groups for our campaign are patients, patients' loved ones and the Raleigh student community.

❖ *Desired Research Data*

PATIENTS

Level of information about the ALSA:

Although many ALS patients currently use the services of the ALSA, not all people living with ALS know that the organization exists to support them. In fact, not all people living with ALS even know that they have the disease because physicians who are not familiar with the disease have misdiagnosed it.

Image and/or other relevant attitudes held about the ALSA:

Those patients who use the services provided by the ALSA view it as a beneficial organization. However, they see room for improvement in fostering increased publicity so that a larger portion of the public is aware of the seriousness of the disease.

Audience behavior relevant to the ALSA:

Ninety to 95 percent of ALS cases are not tied to genes or family history. This means the public is not a homogenous group and patients differ in demographics such as age, race and socioeconomic status. Television and radio are the most practical methods of communicating with this public.

PATIENTS LOVED ONE'S

Level of information about the ALSA:

Their knowledge depends on the amount of information made available to patients because more than likely they will not have heard about the disease through many other sources.

Image and/or other relevant attitudes held about the ALSA:

Since a patient's family and friends are most likely the ones taking care of them, often on a 24-hour basis, they appreciate any relief they can get through the respite care services provided by the ALSA. The organization also functions as a support and resource center for family and friends. It allows them to learn how others in the same situation cope with a loved one who has ALS.

Audience behavior relevant to the ALSA:

Any form of media will be useful in reaching this public, especially the ALSA's website because this public would be more likely than others to be searching out information about the disease. Like the patients, the demographics of the loved ones vary.

RALEIGH STUDENT COMMUNITY

Level of information about the ALSA:

According to our contacts at the "Catfish" Chapter, ALS is not a well-known disease in the community, except for the patients and their loved ones who are affected most personally by it.

Image and/or other relevant attitudes held about the ALSA:

Since the community is generally not aware of ALS, they cannot develop attitudes toward it. If they have heard of the disease they may not realize that although it does not affect as many lives as other deadly diseases, it is a disease with no known cure that could strike anyone.

Audience behavior relevant to the ALSA:

The involvement of this public with the walks is hindered by their lack of knowledge of the disease. Our media communication will target outlets commonly used by high school and college students. Due to their young age, they are more likely to use the Internet and probably watch television more than they read a print media source. They are also likely to gather information from their school campus and their peers.

❖ ***Summary of Research Results:***

The Jim “Catfish” Hunter Chapter has the potential to become a well-known organization in the community and the ability to increase the number of participants involved in the Walks to D’Feet ALS and also the amount of money raised in the walks. Programs such as this must be understood and supported by community members so that money can be raised to go toward research for a cure and the timely distribution of patient services.

A factor that is both an obstacle and an advantage to our campaign is that ALS is not a well known disease. In order to publicize ALSA’s walks, we must always start by introducing information about the disease itself. However, the fact that not many people know about ALS allows us to work without preconceived judgments or stereotypes toward the disease.

II. PLANNING

Problem: It is difficult to publicize an event carried out by an organization that is not well known and that supports patients with a disease that is even less public and therefore is not viewed as a concern or threat to the general public. As a result, the “Catfish” Chapter of the ALSA is not raising as much money to provide patient services, to conduct research, and to increase awareness of the disease as might be possible.

Opportunity: The Walks to D’Feet ALS raise money that helps ALS patients to live longer, more comfortable and more fulfilling lives.

PATIENTS

- ❖ ***Behavioral Objective:*** Following the completion of the spring walks in 2004 we want to have a 10% increase in the number of patients who become involved in some way with the walks.

Strategy: To get information to patients about the walks and how they help raise money for people with ALS.

Tactic 1) Hang posters advertising upcoming walks in the waiting rooms of doctors’ offices and hospitals in Raleigh (For our purposes, we are focusing on the Raleigh walk as opposed to the other walks across the Carolinas.)

Tactic 2) Provide informational brochures describing the purposes and goals of the walks and also how to start a walk team and make a donation to the organization.

Tactic 3) Have a benefit concert two to three months prior to each walk where people will be encouraged to sign up for walk teams on site. For a set price, food, beverages and entertainment will be provided. Our goal is to find sponsors to donate such items and pay the booking fee of the band.

PATIENTS' LOVED ONES

- ❖ ***Informational Objective:*** To increase awareness of ALS as a disease by promoting walk participation in the spring 2004 walks by ten percent.

(Measurable by how many people already participate.)

Strategy: To increase the promotion of the ALS walks directed at people personally affected by ALS.

Tactic 1) Provide a more thorough and detailed web page pertaining to the walks. This page will not only describe what the walks are and their purpose, but will give information about walk dates and times as well as ways to raise money and earn prizes by doing so.

Tactic 2) Have a benefit concert two to three months prior to each walk where people will be encouraged to sign up for walk teams on site. For a set price, food, beverages and entertainment will be provided. Our goal is to find sponsors to donate such items and pay the booking fee of the band.

Tactic 3) Have a person who has been directly affected by ALS and has also been involved with previous walks speak to local religious and community groups about his or her personal experience and the importance of walk participation. We will develop a request form for these speeches that will be given to the community groups in hopes that they will return them with a request to have a speaker come to their meeting.

RALEIGH STUDENT COMMUNITY

- ❖ ***Behavioral Objective:*** To increase Raleigh student community participation in the walks, in hopes of raising the overall amount of money donated to each walk. We will do this by recruiting at least one student to serve on each walk committee in the spring of 2004.

Strategy: To generate publicity about the walks around high school and college campuses.

Tactic 1) Contact National Honor Society chapters and service clubs to suggest the walks as a good service opportunity.

Tactic 2) Target college athletic teams for voluntary participation in the walks by contacting coaches and giving them informational brochures.

Tactic 3) Have a benefit concert two to three months prior to each walk where people will be encouraged to sign up for walk teams on site. For a set price, food, beverages and entertainment will be provided. Our goal is to find sponsors to donate such items and pay the booking fee of the band.

Tactic 4) Contact local television stations to request that they list the Walks to D'Feet ALS on their community calendar as well as the time and location of the benefit concert. Some of these requests can be made on the television station's website. We will develop a contact list for local stations and the person to get in touch with to carry this out.

❖ ***Informational Objective:*** To double the amount of publicity about the walks that is accessible to students in the Raleigh area by the end of the spring 2004 walks.

Strategy: To ensure that each media source has the information needed to publicize the walks.

Tactic 1) Submit news releases to local broadcast and print media, including student-run media.

Tactic 2) Design flyers to give to sororities and fraternities informing them of the dates, times and other details about the walks and how they can get involved.

Tactic 3) Write a feature story to be given to a local newspaper, such as The News and Observer, as a way of reaching a large amount of people through one source.

Tactic 4) Write a pitch letter to be used by a local news organization as an exclusive.

Tactic 5) Contact local television stations to request that they list the Walks to D'Feet ALS on their community calendar. Some of these requests can be made on the television station's website. We will develop a contact list for local stations and the person to get in touch with to carry this out.

Tactic 6) Submit PSA's for local radio and television broadcasts to be announced two weeks prior to the date of the walk.

- ❖ ***Attitudinal Objective:*** To create a proactive attitude in students that increases the number of student participants in the walks and those students who raise money by 20% by the end of the spring 2004.

Strategy: Make sure that the information about ALS is distributed through each school's media channels, and is visible throughout each campus. The information students receive should emphasize the seriousness of ALS as well as the steps they can take in helping patients and their loved ones by participating in walks and raising money.

Tactic 1) Send speakers to local student groups who are interested in community service opportunities. We will develop a request form for these speeches that will be given to the community groups in hopes that they will return them with a request to have a speaker come to their meeting.

Tactic 2) Have a benefit concert two to three months prior to each walk where people will be encouraged to sign up for walk teams on site. For a set price, food, beverages and entertainment will be provided. Our goal is to find sponsors to donate such items and pay the booking fee of the band.

Tactic 3) Distribute attention-grabbing flyers and posters on high school and college campuses in Raleigh.

III. COMMUNICATION

Theme and key message:

All of the tactics focused on inviting people to participate in ALSA's walks. It is important that we spread the word about the disease and also highlight the importance of participation in the walks, as this is one of the major funding sources for patient services. The larger Raleigh media and health care providers, as well as smaller media outlets and community groups will spread this information.

Uncontrolled media:

1) Feature story

This article focuses on an ALS patient's loved one who has participated in a walk. It talks about the disease and the importance of ALSA's walks to increase money for research and health care. This article will be sent to Raleigh's major media outlets as well as NC State's media and major high school papers, radio and/or TV stations.

2) Speaker request form

This form outlines the basic information about ALSA and the walks. It will be sent to Raleigh community groups. The form asks the group to respond if they will be interested in hearing more about the walks and/or how to participate in making an ALS patient's life better. The form also allows the groups to schedule an informative presentation or only ask for information about the walks to be sent to them, without the presentation. We have developed a contact list of Raleigh high schools, colleges, NC State Greek organizations and NC State service groups to where this form can be sent.

3) Venue and vendor information for benefit concert

This list provides the ALSA with information of possible venue and vendor options for each benefit concert. All of the venues and vendors are located in the Raleigh, Durham and Chapel Hill area. The list includes contact information, specific location and a brief description of each venue. For each restaurant and grocery store in the vendor list, contact information and possible products provided are included.

Controlled media:

1) Walk brochure insert

This will be a brief eye-catching insert for ALSA's walk brochures. The walk brochures can be distributed along with the speaker request form, as well as to committee members that will give them to potential walk participants.

2) Flyer for Greek community

We have designed a flyer that includes information about dates, times and other details of walks, as well as contact information for who they can call to get involved. Included is a list of Greek organizations of NC State campus for these flyers to be distributed. The sample flyer design has hypothetical details for a walk in Raleigh.

3) Poster for health care providers

We have designed a poster that advertises ALSA's walks and will be hung in doctor's offices and hospitals in Raleigh. The poster includes specific date and time information for each walk, and included is a contact list of all the family practices in Raleigh and the major hospitals. The sample poster design has hypothetical details for a walk in Raleigh.

IV. EVALUATION

- Have separate registration sheets for student and non-student participants at the check in point for the next Raleigh walk.
- Compare the number of overall participants, student participants as well as money raised to past and future walks.
- The “Catfish” Chapter can perform a communication audit to assess the amount of publicity the walks received and how much of that publicity is accessible to students in Raleigh.
- Create an attitudinal survey to be administered on walk day to students who participate. This should find out how they heard of the walks and what motivated them to participate.

Should money be available for additional evaluation methods, we propose to conduct a focus group with students who have participated in the walks. This should be aimed at finding out what motivated them, how they evaluate the communication before the walks and alternative ways to get more students involved in ALSA’s activities.