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Amyotrophic Lateral Sclerosis Association

<<http://www.alsa.org>>

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ABSTRACT. Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord, leading to muscular atrophy, progressive loss of muscle control, paralysis, and death. This is a review of the ALS Association web site. The site continues to provide ALS patients and caregivers with current resources for managing life with ALS, and it provides researchers and healthcare professionals with access to evidence-based information on the latest scholarship, and guidelines for the most effective therapies and treatments for ALS. The ALS Association website remains an authoritative resource for anyone seeking quality information about ALS.

KEYWORDS. ALS, ALS Association, Amyotrophic lateral sclerosis, Lou Gehrig's disease, neuromuscular disease

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INTRODUCTION

Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's disease, is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord, leading to muscular atrophy, progressive loss of muscle control, paralysis, and death. Approximately 5,600 people in the U.S. are diagnosed with ALS each year. The incidence of ALS is two per 100,000 people, and it is estimated that as many as 30,000 Americans may have the disease at any given time¹. On June 8th, 2013, the Former Massachusetts Governor and U.S. Ambassador to Canada, A. Paul Cellucci, passed away from complications resulting from Amyotrophic Lateral Sclerosis (ALS). Governor Cellucci's ALS, also commonly known as Lou Gehrig's disease, was diagnosed in 2011. Following his diagnosis, Governor Cellucci became an advocate and fundraiser for ALS research. In particular, he worked on a campaign to raise awareness and funds for the UMass ALS Champion Fund, which supports the research lab of a University of Massachusetts Medical School physician-scientist, Robert H. Brown, Jr, DPhil, MD. The campaign has raised nearly two million dollars for ALS research. Upon hearing the news of the Governor's death, University of Massachusetts Medical School Chancellor, Michael Collins, released a statement highlighting Cellucci's ALS activism:

“From the beginning, the Governor refused to allow his challenging diagnosis to prevent him from continuing his lifetime's work of serving and helping others. Indeed, he made a conscious and inspiring decision to use his illness to raise

awareness, galvanize action and spread hope,” said Collins. “In launching the Champion Fund, the Governor’s primary motivation and greatest satisfaction came from knowing that others, now and far into the future, could win the gift of more days as a result of the breakthroughs enabled through the support of his fundraising efforts.”²

In the autumn of 2008, Julie M. Smith wrote a thorough review of the Amyotrophic Lateral Sclerosis Association’s (ALS Association) web site for this column³. As a tribute to Governor Cellucci, the authors would like to build on Smith’s work, and help keep ALS in the public conversation by reviewing some features of the ALS Association’s new and updated web site and its information available for ALS patients and caregivers, researchers, and advocates.

HOME PAGE

The ALS Association recognizes that visitors to its web site include scared patients, recently given a diagnosis of ALS, who are in need of urgent information. Thus, sensitive to these patients and their loved ones’ needs, the updated ALS Association home page (see Figure 1) now has patient services top, front, and center. A drop box lists the contact information for its local ALS chapters, ALS clinics, certified ALS centers, and ALS support groups. Next to this drop box is a search engine for the web site, and a box for users to type in their emails and sign up to receive information.

In the upper right-hand corner of the home page is also a link for users to register with the ALS Association. According to the notice on the web site, the registration information that users enter is used by the ALS Association to provide their web site users with “updates relevant to the site and to our efforts.” However, the ALS Association acknowledges that it also gathers these data “to understand our constituents and to allocate resources.” The web site provides a link to its latest privacy policy for those seeking more information on how their personal data are used. For those wishing to register, on the log-in web page users can create their passwords and usernames, add in their contact and employer details, and list their “ALS Relationship,” which users can select from a drop down menu. A user can select one of nineteen relationships ranging from being diagnosed with ALS to being someone interested in learning about ALS.

The home page is a horizontal menu bar that is divided into eight headings and it has a side bar that with a horizontal menu that is divided into four headings. The web site’s dark on white color scheme and the layout of its menu choices make this an easily navigable web page. While the home page is still crowned by the association’s logo and graphics, the site has removed the busy graphics that once filled this upper region above the menu bar. The home page’s updated main menu bar headings are now divided into two distinct parts. The first set of headings is informational: information about ALS, information about the ALS organization, and information about the ALS organization’s research program. The second set of headings, which are highlighted, is for user engagement web pages. These headings include web pages for information on advocacy, getting involved and helping to fight ALS, and for the donation of funds; the donate tab is highlighted in red and it is the most visible among the main menu’s headings.

The home page's side bar is now divided into four headings aimed at helping users locate the information and web pages most specific to their needs. These include For People with ALS & Caregivers, For Researchers, For Media, and For Healthcare Professionals. The home page's center is still a rotating section of advertised ALS initiatives and highlighted ALS news. Three evenly separated boxes below augment the center page. The lower left box highlights news from the ALS Association and news about ALS. The lower center box is focused on connecting with the ALS Association. Since the last review of this home page, the ALS Association has increased its visibility on social media, with a cluster of social media icons here on the home page and also in the upper right-hand corner of the web site's other pages. These icons link users to the ALS Association's accounts on facebook, twitter, LinkedIn, and YouTube. The lower right box, titled "In The Spotlight," is reserved for highlighting a specific patient resource on the web site. At the time of writing this review there was a resource giving travel tips to patients with ALS.

At the bottom of the home page users will now find the ALS Association's mission statement: "Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support." Under the mission statement are still two icons to help users evaluate the authority of the ALS Association and its website.⁴ The first icon is its National Health Council's Standards of Excellence Certification Program accreditation.⁵ The second is its Better

Business Bureau’s Charity Accreditation, which is up for renewal in July of 2013.⁶ Although the web site has a separate section that details the ALS Association’s five current accreditations, including the HONcode Standard for Trustworthy Health Information for its web site⁷, the ALS Association home page only displays these two icons.

For each web page linked from the home page, there is now a highlighted box with a brief amount of text giving the user an overview of the page’s contents. There is a link at the bottom of this box that users can click to expand if they seek additional information. This design feature, when combined with the lean home page and re-organization of the web site for targeted user groups, makes this web site extremely useful for searching and retrieving information and resources quickly.

FIGURE 1. ALS Association Home Page

[PLACE FIGURE 1 HERE]

ABOUT ALS

The “About ALS” web page (see Figure 2) contains a detailed definition and description of the disease. The web page has a set of graphics to aid in the user’s comprehension of medical jargon, and there is a link to a factsheet with clear and concise information about the disease. This section also provides users with information on symptoms, how one is tested for ALS and how one is diagnosed, how the disease

progresses, and how it is treated. This section also has historical information on the discovery of the disease and how the disease gained national attention after the diagnosis of Lou Gehrig, a famous American professional baseball player.

FIGURE 2. About ALS
[PLACE FIGURE 2 HERE]

ABOUT ALS ASSOCIATION

The “About Us” web page (see Figure 3) informs users about who makes up the ALS Association, its main activities, and its mission, vision and values statements. This section of the web site explains its involvement with fundraising and sponsoring ALS research, advocating for public policy to expand research, care, and services for the ALS community, its work with local ALS Association chapters, and its public education and awareness campaigns. The web page has a section with transparent financial information and disclosures detailing the annual budgets, the amount of funds the Association receives and how it spends these funds, including the amount of each dollar that goes directly to research.

FIGURE 3. About ALS Association
[PLACE FIGURE 3 HERE]

ABOUT ALS RESEARCH

The “Our Research” web page (see Figure 4) highlights news about ALS association-funded research, including “significant research milestones in the fight against ALS.” This section of the web site contains primers on ALS research on topics such as stem cells and it also has a glossary of terms. These educational materials are supplemented with links to webinars on research-related topics and videos of research-related meetings, workshops, and presentations. Lastly, users can access the web site’s news archive, which contains both ALS-related news from journal articles and scholarly communications.

FIGURE 4. About ALS Research

[PLACE FIGURE 4 HERE]

INFORMATION FOR USERS

Under the “For People with ALS & Caregivers” web page , web site users will find patient-oriented publications, and links for living with ALS, treating ALS, and for caring for someone with ALS. There is a phone number for users to call the ALS Association for direct assistance, and a link to an electronic form for users to email the Association with their questions. There is a resource library (see Figure 5) and there are also sections for users with specific needs, such as finding information on getting enrolled in a Clinical Trial, for users with questions or concerns about Familial ALS (fALS), and information and resources for military veterans. The web site still has its

“Newly Diagnosed” section on this page that provides users with critical resources and guides for managing ALS such as the resource “Guide to Living Life with ALS”. Users also can access information on how to enroll in the National ALS Registry, and they can find information to assist with paying for their care, including information about insurance-related issues and navigating Medicare.

As Julie Smith (2008) noted, “A diagnosis of this progressive, ultimately fatal disorder emotionally traumatic for patients as well as their family members and friends” (p.144). Among this web page’s resources are also informational factsheets and webinars for caregivers, including ones that address “the difficult and psychological issues of having ALS and caring for ALS patients.” Under the heading “Library Order Form”, web site users can select among newsletter, factsheets, manuals, books, and DVDs. Users can enter an address to have these materials mailed to their homes. Lastly, this web page contains a new section titled “Stories of Courage”. This section features inspirational stories detailing the lives and achievements of persons living with ALS.

The patient and caregiver resources cover a wide range of practical advice for managing life with ALS. There is a section dedicated to augmentative communication with an overview and information on using computer technology to assist ALS patients with communication such as technology that can track eye movements for communication. In addition to augmentative communication devices, the web site also has a product database for items to help people with ALS with their mobility and independence, such as ramps for wheelchairs and devices to assist with the turning on and off of light switches.

Unique to this area of the web site is the section on genetic testing for ALS -- although about 90% of ALS cases have no family history, there is a small percentage of people with ALS affecting other family members. This section explains some basic information on genetics, and the difference between fALS (Familial ALS) and sALS (Sporadic ALS). Additionally, this section provides information on genetic testing and lists the names and contact information for physicians that might further help users explore their options.

FIGURE 5. Resources For People with ALS & Caregivers

[PLACE FIGURE 5 HERE]

On the “For Researchers” web page, scientists will find information about the ALS Association’s Research Program, opportunities for funding their research related to ALS, and a resource library (see Figure 6). The web site links researchers to the latest ALS grants and awards applications, as well as calls for abstracts and proposals for funding, such as the ALS Association’s Clinical Research Pilot Studies Program. This section also lists the policies and procedures for scientists conducting research under an ALS Association grant. The ALS Association publishes a newsletter for researchers “Research ALS Today” and maintains a Research News Archive for scientific news and journal articles related to ALS. Lastly, it maintains a “Resources for Researchers” section with links to past and upcoming scientific meetings and workshops.

FIGURE 6. Resources For Researchers

[PLACE FIGURE 6 HERE]

The “For Media” web page links journalists and communications professionals with the information to reach ALS Association’s media contact personnel. This section helps connect these professionals with press releases, quick factsheets, and public awareness campaigns. In addition, this section helps journalists to find ALS experts for interviews: “The ALS Association's Communications Department assists the media in reporting on the many dimensions of ALS by coordinating interviews with an array of Association experts in research, patient care, advocacy and public awareness and by providing information about the disease and The Association in a timely manner that is sensitive to breaking news and deadlines.”

The “For Healthcare Professionals” web page connects users with the latest information and guidelines for the treatment of ALS. This section contains a resource library with systematic reviews on the latest and most effective drug, nutritional, and respiratory therapies for treating ALS (see Figure 7)⁸. In addition there is a resource guide for ALS treatment for primary care physicians as well as one for nurses. This section also contains links to a number of webinars and presentations on a variety of treatment-related topics going back to 2010. The Clinical Trial information on the site links to the web site of the Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS), which is supported by the ALS.⁹ This web site provides information on

currently recruiting Clinical Trials and news about current and past trials. It gathers this information from the Clinicaltrials.gov web site.¹⁰

FIGURE 7. Resources For Healthcare Professionals

[PLACE FIGURE 7 HERE]

There are several web pages dedicated to information on fundraising and advocacy. This section of the web site is for users wishing to become involved and active in drawing public awareness and policy changes related to research and curing ALS. The section also exhibits the stories of people who are active throughout the country that are spearheading awareness campaigns and their successful advocacy efforts. Titled “Roadmap to a Cure”, the page features some of the accomplishments of these advocates.

SPANISH RESOURCES AND PAGES

There are certain resources and several web pages of the website that have been translated into Spanish. For the pages, if users click on the “En español” tab, it will take them to a different embedded section of the web site that has a left hand side bar listing all the web pages that have been translated. This particular type of navigation may confuse users, as they might come to expect to find that tab on every page of the web site.

Nevertheless, Spanish-speaking users will appreciate the ALS Association's addition of a Spanish-language content and resources.

CONCLUSION

Since Julie Smith's (2008) review of the ALS Association web site there have been several major changes to its overall design and layout. The home page is lean and the web pages have become much more streamlined. Each web page now has a highlighted box with a brief amount of text giving an overview of the page's contents, which users can then choose to expand if they seek additional information. The web site now logically divides its information among web pages targeted to specific users: patients, caregivers, researchers, and healthcare professionals. Since 2010, the ALS Association has begun collecting webinars hosted by healthcare professionals in addition to its library of document and video files. The resulting ALS Association web site provides its users with improved access to well-organized, relevant, and high-quality health information, with just a few clicks of the mouse.

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