

LEADERSHIP & PROFESSIONAL DEVELOPMENT

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The Creation of a State and National Cancer Resource Web Site for Patients and Professionals

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The Colorado Cancer Resource Guide (CCRG) Web site project was established to enable Colorado patients, families, and healthcare professionals to efficiently and effectively locate cancer resources. The Web site comprises listings of resources from all corners of the state and from national organizations. The founders have gone on to merge the CCRGonline.org listings with resource listings of the Colorado Department of Public Health and Environment's Comprehensive Cancer Prevention and Control Program (CCPCP). This project is an ongoing collaborative effort between the Metro Denver Oncology Nursing Society Chapter (MDONS) and CCPCP.

The project came to fruition through the knowledge, talent, and time of four dedicated multidisciplinary healthcare professionals. A year passed from the group's first meeting to the launching of the Web site. We learned much from the process and modified our efforts as we learned. We encourage professionals in other states to consider establishing cancer resource Web sites for their states. We hope that by sharing our start, process, and end points, we will help other professionals to create similar Web sites for their states.

Background and Getting Started

A common need for cancer healthcare providers and their patients is finding local and national support resources. An example of a guide providing such information is the Utah Cancer Coalition's resource guide, Community Cancer Resource Guide (Huntsman Cancer Institute, 2001). The guide provides a listing of cancer resources in the state from support groups to transportation, insurance, and financial assistance, as well as national cancer resources.

Our project leader, Kim Eisen, BS, a pharmaceutical senior sales representative, led discussions with Colorado oncology nurses and healthcare professionals on how to proceed and concluded that Colorado patients and healthcare providers would benefit from hav-

ing a similar resource listing for Colorado. The project would be patient-focused and not affiliated with any political group.

The project leader submitted a proposal to each of the four Oncology Nursing Society (ONS) chapters in Colorado with the hope of obtaining volunteers. The consensus of the ONS chapters was that the guide would benefit their patients and all professionals' ability to help patients. After the proposal was presented to MDONS, two additional project volunteers, Joni Dunn, MN, RN, AOCN®, CNS, a radiation oncology RN, and Frances Crighton, PhD, RN, a urologic oncology RN, joined the project. The greatest challenge remained: An individual who or group that would provide Web design expertise was required. The group leader thought to seek the involvement of a local college to recruit students to design the project's Web site. We presented the opportunity as a way to fulfill a community service requirement. A patient services assistant at the Denver Leukemia and Lymphoma Society, Jennifer Wayne, BA, read the proposal and offered to be the Web designer for the project. She brought to the project experience in designing computer templates and working knowledge of databases and Web design.

Certain qualifications are recommended for members of task forces wishing to create a Web-based cancer resource site. First, members should have enthusiasm, energy, and tenacity. Second, members having different areas of oncology expertise to overlap knowledge bases would be helpful. Third, all members should have the ability to effectively communicate and e-mail. Lastly, one member must be knowledgeable in computer database software and have Internet expertise. However, the CCRG project members were selected for their oncology background and their interest in the project. Luckily, the CCRG's final team had all of the recommended skills.

Group Meetings

The first meeting was a brainstorming session to decide whether to produce the resource

listing as both a Web-based and hard-copy product. We wanted to provide direct access to each listed resource by linking the listing to the resource's Web site. The Utah committee shared some thoughts regarding its product. The hard-copy format cost thousands of dollars for each printing, and additions or corrections had to be added as separate sheets to each booklet. This feedback led to the decision to create a Web-based product. We believed that a Web site would provide certain advantages. It could be updated with new or changing listings without incurring large costs, and users could print copies of any resource pages.

At one of the first meetings, the name CCRG was selected for the Web site. The group decided to use the Utah Community Cancer Resource Guide as a template (Huntsman Cancer Institute, 2001). The group outlined what resources should be included, assigned categories for data collection, and determined meeting format and modes of communication.

Each team member took an assignment for the collection of data. The group decided to meet monthly and use e-mail as the primary means of communication. The project leader assumed responsibility for sending meeting minutes, meeting date reminders, and reminders of assignments and timelines. Timelines were set, reevaluated, and reset throughout the project. At the beginning of each meeting, assignments were reviewed

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and new tasks assigned. One year from the group's first meeting, the Web site went live. Table 1 is a summary of the CCRG group activities in its first year and a half of existence.

Creation of the Web Site

The CCRG project represents an effort to organize data in one place for easy access by

Table 1. Tasks Accomplished by the Committee in 18 Months

Quarter	Tasks Accomplished
First	<ul style="list-style-type: none"> • Web site content outlined • Web site home page design created • Data-collection and data-entry assignments
Second	<ul style="list-style-type: none"> • Web site name and vanity address obtained • Mission statement entered onto site • Ongoing data collection and entry
Third	<ul style="list-style-type: none"> • Design of Web site pages created • Web site poster created for marketing at a local cancer coalition meeting • Creation of budget to cover annual maintenance and marketing costs • Data entries
Fourth	<ul style="list-style-type: none"> • Marketing tools designed • Abstract submission on Web site to present at the Oncology Nursing Society (ONS) Annual Congress • Loss of database because of a computer crash and no backup • Reentry of data • Proofreading of database entries • More than 400 data listings accomplished • Web site went live as CCRGonline.org on February 19, 2003. • Meeting with Colorado Public Health Department to discuss the merger of resource guides
Fifth	<ul style="list-style-type: none"> • Marketing of Web site's existence at local health events and Colorado ONS chapters • Poster presentation of Web site project at ONS Annual Congress, in Denver, CO, in May 2003 • Work started with Colorado Public Health Department to merge its Comprehensive Cancer Prevention and Control Project (CCPCP) resource guide with the CCRGonline.org listings.
Sixth	<ul style="list-style-type: none"> • CCPCP resource listings added to CCRGonline.org Web site • Web site category modifications • Data collection and entry • Marketing of state and national resource Web listings concept to other state professional groups through professional publications

all. With that in mind, the most essential part of beginning this project was having a uniform method of gathering that data. At first, the majority of the team was more comfortable with entering data into an Excel (Microsoft, Redmond, WA) spreadsheet than into an Access (Microsoft) database, so an Excel data-entry template was designed for the team's use. As time went on and the number of resource categories grew, the spreadsheet form became too cumbersome. An Access database then was developed to streamline the data-entry process and more efficiently track data. Once data entry began, the time to begin creating the Web site came. Before tackling the big project of designing the Web site and going live, a suitable URL (uniform resource locator or Web address) needed to be found and purchased. Available names for use on the Internet can be found simply by typing desired names into a domain search engine. The group's first choice for a name was unavailable, so CCRGonline.org was secured. Because users commonly default to ".com" when typing in a URL, CCRGonline.com later was secured for the site as well. The next step was to register the CCRGonline.org domain name. Several domain registration companies were researched. The ideal company would offer both domain registration and Web site hosting (a service that houses and serves Web site files) with no advertising. We found this in Catalog.com. The total cost for these services for the first year was \$35. As work began in compiling and entering data, the CCRGonline.org home page simply said, "Future Home of CCRGonline."

Web site design occurred simultaneously with data entry. Web development software Fireworks and Dreamweaver (Macromedia, Inc., San Francisco, CA) and Adobe® Photoshop® (Adobe Systems Incorporated, San Jose, CA) were used to design the Web site on a team member's personal computer. Design modifications were presented to the team along the way so that everyone had input. One of the challenging areas of design was fitting large amounts of data onto a single page. Limiting the size of a page is important so that a page can fit on any monitor without the user having to scroll from side to side. Breaking pages into regions and providing navigational elements helped to ease this page overload.

After the first phase of data entry was complete, the first release of the Web site was ready to go into production. Because the Web site has almost 100 pages, the task of building the Web pages was time consuming. Data were collected from the team and consolidated into one database. The database then was sent back out to the team for proofreading and editing. Although this quality analysis of the compiled entries was time consuming, it proved to be essential to ensure accuracy of the listings. Once this quality-control phase was completed, the data were queried according to how they would be categorized

on the Web site. The queries were formatted into workable Web pages using a combination of Microsoft Word and Access, then further refined and formatted on a per-page basis in Dreamweaver. Because the resource pages of the Web site followed the same basic format, Dreamweaver's template feature streamlined a great deal of the page-building process.

A Web site is a work in progress, and redesign most likely will be constant. Once the Web site was published and put into use, some design issues surfaced. The original structure of the site provided direct links to all of the disease and service pages from the home page. This system of navigation proved to be confusing and awkward, and the large number of links available could overwhelm users. As a result, the latest version of the Web site was simplified to have only the captions of Resources for Adult Cancers, Pediatric Cancers, Preventative Care, and About Us as links to the site's support listings (see Figure 1). Pop-up menus were added to clarify the Web site structure and ease navigation.

Merger With Colorado's Public Health Project

We discovered that Colorado's CCPCP had produced a cancer preventive resource guide. The state was requesting feedback about the usefulness of having its guide available on a Web site. The state's public health department was contacted to discuss CCPCP and to introduce our CCRG project. A merger of these two projects would be beneficial to all and would provide one place for patients and professionals to find both state and national resources, as well as information on cancer prevention to promote screening and awareness.

The two projects' data-collection methods were different and required man-hours to convert data into one format. The merger of the two projects resulted in a comprehensive listing of Colorado's cancer resources in one easy-to-use format. The final database system was easier to update and more user-friendly and provided proofreading for spelling and grammar corrections. Both groups benefited from the merger. CCRG gained state funding for expenses, and the state benefited from gaining professional volunteer hours to assist with data collection, ongoing data entry, and maintenance of the Web site.

Budget

The CCRG team was extremely fortunate to have a member who was able to provide the skill and time needed to develop the Web design, thus saving \$3,000 to hire a Web design professional. MDONS received a \$2,500 grant for the CCRG project from Wyeth Pharmaceuticals (Collegeville, PA). This grant funded the project's annual operating costs for two years and 15,000 pieces of promotional print material. The annual cost to maintain the site, including the domain registration annual fee,

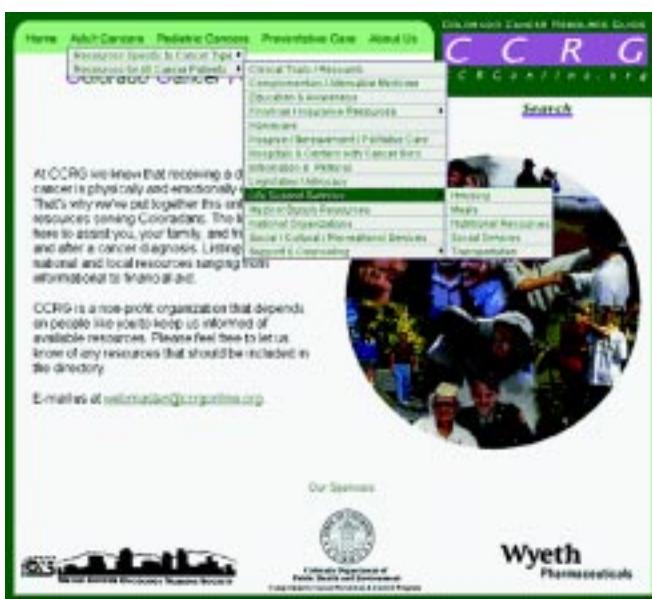


Figure 1. CCRGonline.org

Web hosting membership fee, search engine annual registration fee, and storage fees, is \$208. The largest expense was promotional material. The reprinting of promotional laminated bookmarks has been the group's number one promotional item. The bookmarks are cost effective and provide a large enough surface space to allow for easy reading. The state's CCPCP currently is funding the project expenses. The present marketing plan calls for the distribution of sign holders to offices and community centers. The cost for the signs is estimated to be \$1,000.

Marketing

The project's marketing developed into three separate tiers. The first tier was to educate oncology nurses about the existence of the Web site. Presentations about CCRG were made to Colorado's ONS chapters. ONS members were provided with bookmarks and business cards to take back and distribute to their patients. The second tier consisted of providing local health programs and health centers with CCRG business cards and bookmarks to distribute at their functions and have available for their patients, respectively. The local health programs were the Day of Caring, the Leukemia and Lymphoma Society, and the Sally Jobe Breast Center. The third tier involved contacting administrators of local libraries to ask them to link their search engines to the CCRG Web site. In the near future, doctor's offices and centers will be provided with signs about the CCRGonline.org Web site and holders for CCRGonline.org bookmarks and business cards.

End Results

Currently, the CCRGonline.org Web site has almost 100 pages. See Figure 2 for cat-

egories of the listings included on the Web site. The breast cancer category had so many listings that a separate pop-down menu was created to organize them; therefore, it is separated to have its own column in the table.

Project Evaluation

Evaluation of the CCRG project is ongoing. The Web site is monitored via multiple avenues, including reviewing e-mails to the Webmaster, tracking the number of site visits, and soliciting feedback from the field. An e-mail link to the Webmaster is

development. By routinely executing searches with several different search engines, we find that our site is gaining visibility. However, this is an area that needs further attention.

Lessons Learned

The CCRG group learned quickly that a strong leader was needed to keep the group on track with the project. Problems occurred, such as computer crashes, lack of data-entry backup, conflicting data-entry items, and overlapping of data. Excel program data entries became cumbersome, and a switch to an Access program for data entry became necessary. All of these problems resulted in multiple data entries. The group volunteered time and talents to the project but learned that finances were needed for marketing the project to patients and healthcare professionals. Late in our endeavors, we discovered a National Institutes of Health Web site that offered advice on the development of Web sites (www.usability.gov). It offers information on designing usable, useful, and accessible Web sites. We recommend that all professionals who are developing Web sites visit this site. Finally, an unexpected lesson was learned after compiling resources from across the state. We discovered that cancer support care resources were lacking in different areas of the state. This is a kind of healthcare disparity and is vital information to help efforts to increase local resources for all Colorado patients with cancer.

Implications for Oncology Nurses

As more and more patients use the Internet, the need for reliable, easy-to-use health information and resource Web sites

About Us	Retinoblastoma	Financial and Insurance	Support Groups
Who We Are	BMT	Financial Resources	Counsel Services
Contact Us	Brain	Insurance Resources	Survivor Network
Adult Cancer Types	Cervical/Ovarian/Uterine	Pharmaceutical	
Breast	Colon/Rectal	Home Care	Preventive Care
Brain	Histiocytosis	Hospice/Bereavement/	All Cancers
BMT (bone marrow transplant)	Kidney	Palliative Care	Breast
Cervical/Ovarian/Uterine	Leukemia/Lymphoma	Hospitals/Centers With	Cervical/Ovarian/Uterine
Colon/Rectal	Sarcomas	Cancer Services	Lung
Kidney	Ewing's	Information and Referral	Melanoma
Leukemia/Lymphoma/ Myeloma	Myosarcoma	Legislative/Advocacy	Prostate
Lung	Rhabdomyosarcoma	Life Support	Other Cancers
Melanoma	Other Sarcomas	Housing	
Oral/Head/Neck	Testicular	Meals	
Prostate	Other Cancers	Nutritional	
Sarcomas		Social Services	
Testicular		Transportation	
Other Cancers		Medical Supplies	
Pediatric Cancer Types		National Organizations	
Neuroblastoma		Social/Cultural/Recreational	
		Support and Counseling	
		Hotlines	

Figure 2. Categories of Information Listed on the Web Site

grows (Fogel, 2003). Patients now are able to access health information and resources while they wait for physician appointments. Providing patients with easy access to community resources is important. CCRGonline.org offers patients quick lists of such resources, ranging from educational to supportive care services. The Internet provides a great venue for delivering information to patients. Once patients access CCRGonline.org, they are amazed to learn how many local programs exist for them in their community

(Weis, 2003). Professional staff also benefit from this Internet resource guide. For example, CCRGonline.org can be used to identify hospice organizations to obtain services for patients. Lastly, the Web site can and has educated many nurses about the resources that are available for their patients. Nurses are working together to help patients receive the best and most comprehensive care possible. We invite professionals who would like more information or advice about creation of a similar resource Web site for their states to

contact us via the Webmaster at CCRG online.org.

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