Introducing the Global Advocacy Leadership Academy (GALA): Training Health Advocates around the World to Champion the Needs of Health Care Consumers

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Abstract—**Patient advocacy can make significant contributions to health research by ensuring that efforts are patient-focused and help promote cooperation between all relevant sectors of the health care community. Yet, the development of effective patient advocacy organizations demands strong leadership, establishment of active collaborations with key stakeholders, and careful management of fiscal and personnel resources to enhance health outcomes. This presentation describes the development and implementation of an innovative training academy to prepare cancer advocacy leaders, both domestically and internationally, by helping them carefully consider strategic health advocacy processes, roles, and responsibilities. The Global Advocacy Leadership Academy (GALA) will provide participants with a comprehensive overview of the modern health care system, identifying critical constituents and stakeholders, and examining interrelationships between key individuals and organizations. Strategies for fostering meaningful communication, cooperation, and coordination between patient advocacy organizations and other stakeholders related to health, including consumers, other advocacy groups, clinicians, government officials, researchers, and private industry representatives, will also be explored. For example, patient advocacy organization leaders will learn about communication strategies for working effectively with researchers and clinicians to support prevention, detection, treatment, and survivorship efforts that will benefit patients. Patient advocacy organization leaders will also explore strategies for raising funds and increasing funding for health research. They will learn about clinical research, health regulatory systems, community organizing, as well as drug and technology development and approval processes from basic research to clinical practice. Exemplar models of successful patient advocacy organization leadership will be described and evaluated as GALA case studies that illustrate effective health advocacy.**

Keywords-patient advocacy organizations; leadership; media relations; corporate relatioms; health care systems; government agencies; stakeholders; personnel management; health promotion.

I.   INTRODUCTION

The Global Advocacy Leadership Academy (GALA) is a new public health educational initiative designed to facilitate needed training and support for leaders of health advocacy

organizations around the world. Leadership of health advocacy organizations is a complex enterprise that demands a tremendous amount of specialized knowledge about the health care system and constituent groups, adaptability to evolving health care systems, and the ability to reach, influence, and collaborate with a wide range of individuals from different sectors of the health care system through strategic health communication. The GALA program is introducing a unique international training and support model to prepare health advocacy leaders to meet the challenges of building and sustaining strong consumer advocacy organizations to champion the needs of patients and their caregivers within the modern health care system.

Effective leadership of health advocacy organizations is a demanding and complicated enterprise. While many aspiring advocacy organization leaders are passionate about helping to improve the modern health care system and to represent the needs of health care consumers, they may not be particularly well prepared to meet the demands of achieving these goals. The development of the GALA program grew out of the work of its founders (Gary Kreps and Paula Kim) in advising new health advocacy leaders from around the globe to achieve their goals. We recognized the many challenges that advocacy leaders face in influencing health research, health care practices, and health care policies and decided the best way to assist these leaders was to develop a formal system (GALA) for building advocacy organization leadership capacity. Moreover, we realized that health advocacy organizations were situated within a global health care system, concerning many of the same health care problems that affect consumers around the world. There was a tremendous need to link health advocacy organizations within a global advocacy network to promote international cooperation and collaboration for achieving shared goals of consumer empowerment and support within an interdependent, challenging, and evolving global health care system [1]. This paper outlines the goals and strategies of the GALA program for supporting the development of effective and influential health advocacy leaders and organizations.

II. MEETING HEALTH ADVOCACY CHALLENGES

The GALA program is designed to help leaders understand the unique sociopolitical structure of the modern health care system, both on a broad societal level and also within the unique health issue communities that address the specific areas of direct interest to different health consumer groups (for example, communities interested in lung cancer, diabetes, Lupus, kidney transplantation, hemophilia, or other challenging health issues). Strong and effective health advocacy organization leaders need to understand the lay of the land within the rapidly evolving health care system so they can help influence health care policies and practices to reflect the needs and goals of the health care consumers they represent.

Health advocacy leaders also need to know which specific organizations and individuals exert influences in the delivery of care, development of health policies, conduct of health research, and translation of research into health practices within the health domains in which they want to support the needs of consumers. Effective leaders must build collaborative relationships with key organizational representatives to exchange relevant information and cooperate on issues of importance to consumers. There is a daunting amount of information to learn to prepare for effective advocacy group leadership and a vast number of relational connections to establish for new advocacy leaders. Often, new health advocacy leaders have serious information deficits and limited relational connections that limit their abilities to accomplish important consumer support goals.

The GALA program is introducing new and relevant training, support, advising, and collaboration training programs to help health advocacy leaders build their knowledge base and learn how to work effectively with key representatives of different segments of the health care system. GALA will help connect advocacy leaders to relevant health researchers, educators, government and regulatory agency officials, health care delivery system personnel, health product and services corporation leaders (pharmaceuticals, health equipment, medical devices, insurance companies, and health informatics firms), media, representatives, as well as leaders of other related advocacy and support organizations. Not only is the GALA program designed to teach leaders about these different relevant segments of the health care system, but the GALA program will introduce health advocacy leaders to key representatives of these health sectors to initiate development of cooperative relationships for achieving advocacy goals.

The GALA program is also designed to help educate advocacy leaders about the nature of health research, including how research is funded, who conducts health research, how research results are reported, how to make sense of health research findings, and how research is translated into relevant health care policies and practices. The GALA program will help advocacy leaders understand the intricacies of the modern health care system, including the design of health care delivery systems, the key roles performed by different professionals and support personnel working within the health care system, and the evolving policies governing health care delivery and reimbursement. The GALA program will also educate advocacy leaders about the development of government legislation for health care policies, programs, and research, corporate influences on the health care system, and the unique roles performed within the health care system by professional associations, regulatory agencies, educational institutions, support organizations, foundations, and other assorted non-profit, for-profit, and government agencies.

III. HEALTH INFORMATION DEMANDS

Access to and effective use of relevant, accurate, and timely health information is critically important for guiding the important health-related decisions that consumers and providers must make across the continuum of care to

promote health and well-being [2]. This includes decisions about the prevention of health risks, health promotion behaviors, the detection and diagnosis of health problems, health care treatment strategies, and best practices for living with health threats (successful survivorship) [3]. Yet, health information is complex, with many different kinds of health risks, each with different causes, stages, symptoms, detection processes, and treatment strategies. Health care knowledge is rapidly evolving with advances in research and applications concerning etiology, prevention, detection, diagnosis, and treatment of health problems.

Health advocacy organizations have the potential to help break through the complexity of health and health care by disseminating relevant, timely, accurate, and clear health information to consumers to help guide informed health decision making. However, there are significant barriers to the dissemination of health information, especially for at-risk populations, due to limited access to health information, health literacy challenges, limited education levels, and the complexity of health research and health care processes [4]. The GALA program is designed to help health advocacy leaders develop a wide range of necessary knowledge and skills to enable them to achieve important consumer goals. For example, GALA can help health advocacy leaders learn how to support the information needs of the health care consumers they represent, providing these consumers with access to relevant, timely, and accurate health information. The GALA program is also designed to help advocacy organization leaders learn how to promote and advocate for increased funding for relevant health research needed to improve prevention, detection, treatment, and survivorship for the consumers they represent.

The GALA program will help leaders learn how to run effective advocacy organizations to serve the needs of their constituents and influence health practices. Strategies for recruiting, mobilizing, and serving the needs of organizational volunteers and personnel will be examined. Fund raising, investment, and fiscal management demands will be carefully examined. Strategies for using funds wisely for disseminating information, influencing legislation and policies, and planning and implementing influential health campaigns will also be examined.

The GALA program will help advocacy organization leaders learn how to disseminate relevant health information through a variety of media to raise awareness and educate health policy makers, health care administrators, providers, and consumers about the health issues of concern to their constituents. The GALA program will help advocacy organization leaders learn how to lobby legislators, regulators, and health care administrators to improve health care policies and practices. The health advocacy leaders will learn how to provide needed support and assistance to consumers confronting challenging health care problems, as well as to support the needs of their caregivers, family members, and loved ones. Perhaps most importantly, the GALA program is designed to promote local and global

cooperation within the health care system to support health promotion, prevention, early detection, the best treatments, and successful survivorship for the health issues of concern to their constituents.

IV. THE UNIQUE GALA DELIVERY MODEL

The GALA program is designed to provide advocacy leaders with relevant information and strategies for working effectively with key internal and external groups. For example, training programs will be conducted concerning development of effective relationships and collaborations with media representatives, government representatives, corporate leaders, researchers, and health care system representatives. Moreover, the GALA program will provide advocacy leaders with ongoing information support, consultation, updates on new opportunities/constraints, and continuing education to meet changing needs and refine advocacy knowledge and skills.

GALA programs will be delivered in several different complementary ways. Advocacy leaders will be invited to attend training programs conducted at a centralized site (George Mason University), where they will also be introduced to relevant government, corporate, and health care system representatives, researchers and scientists, legal, fiscal, and administration advisers, campaign planners and fundraising experts, as well as experienced and successful health advocacy group leaders. In addition to centralized training programs, GALA program educators will travel to advocacy organizations in different parts of the world to provide on-site training programs. Arrangements will be made on demand to provide individual follow-up personal consultation with advocacy leaders to address specific emergent issues and concerns. Field experience opportunities will also guide advocates to participate in important meetings, conferences, and other relevant events, as well as to examine with GALA personnel the implications of these meetings. GALA is also proposing to link advocacy leaders and their constituents with an online information system (a collaboratory) to provide continuous support, on-line educational modules, repositories of health information documents, case studies, and media, as well as networking/collaboration opportunities for solving problems and developing new health advocacy initiatives.

The GALA training programs will model effective health advocacy leadership strategies. Leaders will learn how to establish and build effective advocacy organizations. They will learn how to recruit volunteers, organization members, and support staff. They will develop strategies for collaborating with other advocacy groups, locally, nationally, and internationally. They will develop skills for establishing working relationship with government representatives, corporate leaders, media representatives, educators, and researchers. They will also learn how to raise, manage, and invest funds for achieving advocacy goals.

The global nature of the GALA program is designed to promote international cooperation and collaboration for

addressing advocacy issues, sharing resources, and implementing new policies and practices within the health care system. Advocacy leaders from different parts of the world who may be addressing similar issues will be linked to share information and resources for addressing these common issues. These leaders will be encouraged to build international collaborations for influencing global health practices and policies. The GALA program will combine support for leveraging research, theory, policies, and innovative applications to promote development of robust and adaptive advocacy programs to support the needs of health care consumers and their caregivers.

V. GALA DEVELOPMENT ACTIVITIES

To promote the growth and development of the GALA program, new strategies are being examined for seeking government and corporate support for GALA training and outreach programs. Survey data are being collected from key members of the advocacy, health care, government, and corporate communities to expand understanding about the unique training needs of advocacy organization leaders and the best strategies for meeting these training needs. GALA team members are identifying leading experts to work with the program to serve as mentors and trainers for aspiring advocacy leaders. New training modules, educational materials, and instructional guides are being designed and refined to use with the program. The GALA online collaboratory system is being designed and information is being collected to include in the collaboratory's online repository of documents, case studies, articles, research and

funding opportunities, advocacy resources, and media programs. Information about the GALA program is being disseminated to key individuals and organizations around the globe to increase awareness and support for the new and exciting GALA health advocacy leadership activities.

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