



## History of NAHAC

by Joanna Smith, LCSW, MPH, CHA, Founder of NAHAC  
*With special Acknowledgement to the Shelter Rock Group*

The world of Healthcare/Patient Advocacy was not in the general public's consciousness when I started my own healthcare advocacy practice in 2005. I had been looking for other people who were practicing as Healthcare/Patient Advocates and Navigators, assisting families and individuals of all ages in navigating through complex medical situations. It seemed that everyone I spoke with was unaware that independent healthcare advocacy existed as a profession. I started to think, "there MUST be others doing what I'm doing" and I imagined that, if I started a National Association, both the public and other advocates would find it, and it would be a way to help the public learn how to advocate for themselves and how to connect with people that could assist them. I had met a few people through searching the internet, but I knew there must be more. There were!

### **What is a Healthcare Advocate?**

As I considered starting the organization, the question of what kind of work a health advocate might do led me to develop the following definition of Healthcare Advocacy: "Healthcare Advocacy" shall mean a Healthcare Advocate providing services including, but not limited to, assisting clients to make informed choices regarding available options and resources within the healthcare system, working with clients at all "levels of care" in the healthcare system, ensuring that people understand diagnoses and procedures, assisting in considering alternate treatment options, clarification of personal values as they relate to medical treatments, coordination of medical services, case management, discharge planning, arrangement of community-based services, assisting with complex medical decision-making, helping arrange second opinions and

securing services from other medical systems, and advocating for clients with insurance systems and healthcare providers. Healthcare Advocacy shall not include: (1) giving second opinions; or (2) direct, hands-on medical care of any type, including, but not limited to, physical exams, blood draws, wound care, and surgical procedures.

## **Early History**

While researching the history of “healthcare advocacy”, “patient advocacy” and similar terms, I came across a succinct history of the Advocacy movement on the web site of Sarah Lawrence College. Subsequent conversations with both Maggie Hoffman and Marsha Hurst enhanced my understanding of a small group of Health Advocates who had already come together in 2006 in Shelter Rock, Long Island, New York to discuss the formation of a Health Advocates Association. That proposed organization intended to include individual health/patient advocates, but not health advocacy organizations. In reading about the gathering, I realized that much of the thought about creating an organization had already occurred, but the organization had not become a working system because of differing views of who could be a member. I am indebted to conversations with Maggie Hoffman and Marsha Hurst on the origins and thoughts of this talented group of professionals. These conversations helped clarify the focus and structure that led to the current design of NAHAC.

The issues raised by Shelter Rock Group (what an Association would do, who could join, what a Code of Ethics should contain and how to address the issues of Education and Certification/Credentialing of advocates) led me to think closely about what an Association should try to accomplish. My background in Public Health was formative in helping me understand that the goal of Healthcare Advocacy is to improve the public’s understanding of their healthcare choices, and their ability to navigate through complex medical situations for themselves or a family member. The mission of this organization would be twofold: to empower advocates and consumers to navigate our healthcare system effectively, and to facilitate informed decisions around high quality, timely, safe and affordable care. If the mission statement included those two facets, then, membership should be open to anyone: professional advocates, consumers and those in academia and public policy. The diversity of members from different orientations would sharpen our view of the issues and solutions in this emerging field.

So I created NAHAC (NA' AC—the H is silent!) on July 15, 2009 as a private Association with membership open to the general public, healthcare advocates, patient advocates, patient navigators, legislators, and those in public policy and academia. I was hoping to create the national presence for the world of advocacy, whatever name it might go by. NAHAC started as a grassroots organization, dedicated to improving the consumer healthcare experience. We remain dedicated to that principle today.

The NAHAC website first launched in July 2009, with a call for interested parties to join and become Founding Members. Twenty four people joined as a Founding Member in the space of a few weeks and we all owe them a debt of gratitude for their foresight and energy. Founding Members included: David Behnke, Pat Bramlage, Shelley Cooper, Beth Droppert, Martine Ehrenclou, Sharon Gauthier, Raquel Gabriel-Bennewitz, Michelle Gilmore, Marsha Hix, Kristen Jones, Sima Kahn, Michael Knappman, Susan Lilly, Karen Mercereau, Jay Narayan, Sharon Parkinson, Maggie Radany, Jane Neff Rollins, Elisabeth Schuler Russell, Dianne Savastano, Kenneth Schueler, Joanna Smith, Laura Weil, and Ricka White-Soso.

We held our first executive committee elections in September 2009, and elected the following officers: President, Joanna Smith; Vice-President, Elisabeth Schuler Russell, Secretary Ricka White-Soso and Treasurer, Maggie Radany and Founding-Member-at-Large Laura Weil. This intrepid group took on the task of growing the organization and the profession.

The years of 2010 and 2011 were filled with two more annual conferences: one in Washington D.C., and the third back in Berkeley, CA. At the same time, the field of Healthcare Advocacy, Patient Advocacy, Patient Navigation and Nurse Navigators continued to expand. The Executive Committee began to discuss the possibility of converting NAHAC into a non-profit 501c3 Association, organized around two goals: to assist the public in learning how to navigate through healthcare situations and to provide education to professionals in the field in the skills needed to excel in advocacy. We applied to become a 501c3 organization in August of 2011, and the IRS granted NAHAC non-profit status, retroactive to June of that year. NAHAC is incorporated in the State of California as a non-profit organization.

In the initial years of the organization, we focused on creating a community composed of people practicing advocacy and consumers interested in learning about advocacy for themselves. We

held conferences, developed monthly educational roundtables, and served as a networking base for people in the field. We call ourselves by many different names, but our goals are the same.

As our Board of Directors began looking at the profession, we determined that our first action would be to create a Code of Ethics as the first step toward defining the practice of healthcare/patient advocacy. Kenneth Schueler and Jason McNichol took the lead in forming a committee and developing the Code of Ethics. It was finished shortly before Kenneth Schueler died, in 2011. We remain indebted to Ken for his leadership in creating the cornerstone Code of Ethics.

In tribute to Ken, in 2011, we established the Kenneth Schueler Memorial Fund. NAHAC, as a 501c3, is able to accept donations in Ken's name to the Kenneth Schueler Fund. Your gift will be used to expand the Association's Educational Activities and to realize NAHAC's mission in Ken's honor—to educate consumers and to professionalize the emerging healthcare advocacy movement.

In the last two years, NAHAC has expanded its public offerings to include a selection of Free Public Podcasts as well as extensive additional podcasts for Full Members of NAHAC. We also now offer a virtual Medical Library, a Directory of Practicing Advocates, a LinkedIn Group, exciting Conferences and "Ask an Advocate" Forums. Our current Board of Directors is comprised of nine members of the Association. Our officers include President, Vice-President, Secretary and Treasurer plus a non-voting position of Past President.

As we approach our Fifth Annual Conference (Chicago, October 30-November 1, 2014), we are excited to announce that Best Practices for Healthcare/Patient Advocates and Navigators will be a key focus of the gathering. The combination of our Mission Statement, Best Practices and Code of Ethics creates the foundation for this emerging profession, wherever Advocates might choose to work.

We remain committed to the creation of a more effective healthcare delivery system, and to the continued emergence of consumer-focused healthcare.