

Much of National Patient Advocate Foundation's success comes from the people who volunteer for us. Our volunteer network is made up of dedicated, passionate people committed to improving health care delivery experiences for patients and families living with serious and chronic illnesses. Our volunteers are current and former patients, caregivers, health care professionals and other people who care about improving equitable access to affordable, high quality health care in our country. They work at the local, regional and national level to put people at the heart of health care by helping NPAF advance its person-centered and family-focused agenda that prioritizes treating the person beyond the disease.



Volunteers can customize their experience to match their interests, skills and schedule. Some devote just a few minutes a week by responding to action alerts, while others commit several hours or more each month participating in webinars and community events, developing new skills through training, and sharing their expertise and their stories in various venues to influence health care policies and practices. We offer a range of in-person and virtual patient advocate and grassroots network education and skills training options for volunteers, as well as frequent updates on active and emerging health policy issues. Below are descriptions of the coordinated advocacy programs NPAF offers support volunteer education and activation.

Grassroots Advocacy Network

Our grassroots network of volunteers help to bring the perspectives and experiences of patients and caregivers to the forefront of health system delivery reform. These volunteers are equipped to pursue community outreach and education on critical health care concerns, cultivate relationships with key policymakers and other influential stakeholders, and motivate them to act through effective public policy advocacy that ultimately improve patient and family quality of life and care quality. NPAF provides the training, resources and take-action opportunities grassroots volunteers need to:

- Contact and meet with community partners, federal and state legislators and other policy makers to highlight priority health care issues affecting patients and caregivers coping with serious and chronic illness and press them for collective action;
- Share their personal stories through media outreach, testimony, and/or serving on advisory councils or taskforces to help implement meaningful health reform; and

- Educate stakeholders in their communities about critical health care issues, recruit them to join our growing grassroots network and mobilize coordinated action.

Patient Advocates

Our patient advocate program cultivates highly trained volunteers through an in-depth, comprehensive skills development curriculum and hands-on workshops that prepare them to serve as health care change agents at the individual, community and system levels. These advocates help advance the culture of advocacy and represent the voices of patients and caregivers as advisors working with hospitals, clinical practices and local, state and national health care agencies and initiatives, task forces and panels. Topics featured in the patient advocate development series include:

- Health and Patient Advocacy Overview
- Advocacy Principles, Responsibilities and Ethics
- Using Patients' Experiences to Inform Advocacy
- Building Momentum – NPAF Perspectives on Policy and Advocacy
- Palliative Care in Prime Time – Building Better Bridges to Quality of Life



Faye Hollowell (left) of Cordova, TN and Becky Barnes of Louisville, KY in front of the US Capitol as part of the Patient Quality of Life Coalition Lobby Day, June 2018.

Trainings and Events

NPAF's trainings and events support volunteers in learning and honing effective advocacy skills and strategies for integrating person-centered care principles and skilled communication techniques in all care settings. These activities emphasize community education, outreach, engagement and activation in collaboration with key partners and stakeholders. Specific initiatives include:

- **Webinars:** NPAF regularly offers webinars on a variety of topics for both professional and lay audiences. Information on upcoming webinars and other training offerings can be found on the [website](#) as well as by signing up for our mailing list.
- **Policy Consortium:** In the Spring and Fall, these events in Washington, DC bring together a diverse group of advocates, experts and grassroots activists to discuss the most pressing issues of the day, along with Patient Advocate Foundation case managers and their patients. A central aspect of these consortia consistently highlights current, real-world data gleaned from our PAF/NPAF research about patient and caregiver needs and quality care priorities.
- **Annual Patient Congress:** Each year, NPAF volunteers from across the country are selected to participate in Patient Advocate Foundation's Patient Congress held in

Washington, DC. This event provides a unique opportunity for our volunteers to come together and network, develop and share their personal stories, receive valuable skills-building and issue training through interactive workshops and education sessions, discuss and plan collaborative community engagement activities to pursue back home, and learn the latest on pressing policy issues while also having the chance to participate in Congressional meetings on Capitol Hill.

- **Skilled-Communication Workshops:** NPAF also works closely with community groups across the country to offer a series of skilled-communication workshops for the people they serve. We discuss the importance of telling your story—both at the individual and collective level, and highlight issues specific to those communities and the programs that are working to address these challenges. The workshops provide an opportunity for participants to learn valuable skills, like shared decision-making, while engaging in open, interactive discussions about what matters to them.
- **Patient Action League:** This community outreach and education program provides information and innovative skills training for grassroots advocates in the field, engaging patients, caregivers, health professionals and stakeholder partners in dynamic communication and care planning activities that reinforce the importance of treating the person beyond the disease. These activities help participants understand and appreciate the expertise and influence they already have for promoting person-centered care principles and practices, providing new skills and tools that will position them as effective grassroots network advocates working together toward a shared quality care cause.
- **State Advocacy and Awareness Campaign:** Through this coordinated series of state policy issues briefings and associated grassroots activation in the field, NPAF volunteers have the opportunity to influence meaningful person-centered policy change in their state capitals. NPAF supports our volunteers every step of the way to mobilize with community coalition partners in meetings with state legislators and other policy makers on priority issues such as step therapy, balance billing and integrating palliative care.

Interested in becoming a NPAF volunteer?

We need your passion, your voice and your commitment to help us put people at the heart of health care. We are eager to hear from you!

Please contact our Director of Grassroots Advocacy Director, Donna Guinn (donnag.kaufman@npaf.org), to learn more about how you can help support and advance NPAF's person-centered agenda.