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**PVP Resource List 2019**

Below is a snapshot of patient and family-centered organizations with whom we’ve worked. Some are policy-oriented and work mostly with organizations or clinicians. Others represent communities of patients, and offer them support, education, networks, and/or assistance. (This isn’t a comprehensive list…we’re just trying to help you find what you need!)

**Our advice:**

1. **If you’re researching your medical condition online, the results can be overwhelming! You can help filter out misinformation, agenda and advertising by sticking to websites that end in .gov or .edu. or those of reputable organizations like the** [**Mayo Clinic**](https://www.mayoclinic.org)  **or the** [**World Health Organization**](http://www.who.int/en/)
2. **Joining an online patient community, including those listed below, can be a great way to connect with other patients. Please read up on them to learn how your data and information will be used.**
3. **The most basic advice if you’re grappling with a new diagnosis (other than to do your research) is to write down your questions in advance of appointment, and bring a friend (with a notebook, able to take good notes) with you to every appointment if possible.**

**We hope this helps!**

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| Group | Focus  | Who | How they can help |
| [Consumers Advancing Patient Safety](http://www.patientsafety.org/index.html)  | Consumer-led nonprofit organization formed to be a collective voice for individuals, families and healers who wish to prevent harm in healthcare encounters through partnership and collaboration | Multi-stakeholder board (hospital, physician, research, patient) | Consumer-led patient safety organization |
| [CureTogether.org](http://curetogether.com) | An online platform that compares the efficacy and performance of hundreds of health conditions  | Recently became part of 23andme.com | A free and anonymous way to learn from people going through the same thing |
| Condition-Related Advocacy Groups (Heart Ass’n., Diabetes Ass’n, Epilepsy, Cancer, etc.) | Focused on advances and treatments of their respective diseases | Multiple | Condition or Diagnosis-related information and advocacy |
| [The Empowered Patient Coalition](https://empoweredpatientcoalition.org) | Online resources for patient empowerment and patient safety | Nonprofit organization formed by CA patient advocates who learned a great deal about the health care system through the years-long medical treatment of their child  | Excellent online resources |
| [Inspire.com](https://www.inspire.com) | Community of diagnosis-specific support groups | Contracts with industry including pharma and biotech | Allows patients to connect with others who have same diagnosis |
| [Institute for Patient and Family-Centered Care](http://www.ipfcc.org/) | IPFCC coaches and facilitates patient- and family-centered change in all health care settings | Multi-stakeholder board (hospital, physician, research, patient)  | Includes robust patients and patient presenters/advocates in their conferences |
| [Lown Institute](http://lowninstitute.org)  | Reducing overtreatment, encouraging “Right Care”: “A ‘think tank’ advocating a radically better and uniquely American health system that overturns high-cost, low-value care” | Multi-stakeholder | Activist in spreading “Right Care” around the nation |
| [MITSS](http://mitss.org)(Medically Induced Trauma Support Services) | Offers support, training and programs for those who have experienced medical trauma and to organizations that desire training to handle incidents of trauma | Nonprofit founded in 2002 in Boston area by a patient in the wake of her own medical trauma; has since gained widespread support  | Confidential telephone support and group support for those who have experienced medical trauma |
| [Patient Orator](https://www.patientorator.com/) | Over 100 thoughtfully produced video interviews/discussions to date | Aims to raise voices of those impacted by healthcare inefficiencies to activate change | Contact to discuss your story |
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| [Patients Like Me](https://www.patientslikeme.com/) | An online platform where patients share and learn from real-world, outcome-based health data. | Multi-stakeholder board (hospital, physician, research, patient) | Learn from the experiences of patients with the same diagnosis |
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| [Partnership for Patients](https://partnershipforpatients.cms.gov) | Multi-stakeholder effort to improve hospital safety, care transitions and patient engagement | Government, doctors, nurses, hospitals, employers, and patients; Formed by CMS (federal government) | Policy work with medical stakeholders and regular public webinars that include patient speakers on given relevant topics (medication error, etc.) No direct assistance to individual patients |
| [PFCC Partners](https://pfccpartners.com) | Bringing PFACs (Patient and Family Advisory Councils) to hospitals and other health care organizations  | Founded by patient advocates, close relationships with providers | Offers systems, tools and webinars to  |
| [Planetree](https://planetree.org/) | Mission-based not-for-profit that partners with health care organizations around the world to transform how care is delivered so that it is person-centered. Founded 40 years ago by a patient | Hospitals and other provider members | Powered by over 50,000 (and counting) focus groups with patients, families and staff, can coach and facilitate culture change. Heavy emphasis on patient voice at their events. |
| [Schwartz Center for Compassionate Healthcare](http://www.theschwartzcenter.org) | Focused on reconnecting physicians, nurses and other clinicians with the human side of health care | The legacy of Boston attorney Kenneth Schwartz | Offers “Schwartz Rounds” to bring doctors, nurses and other caregivers together to discuss the human side of healthcare. Also offers education and support programs |
| [Smart Patients](https://www.smartpatients.com) | An online community where patients and their families learn from each other about their diagnoses, treatments, clinical trials, etc. | Founders believe “the next tipping point in medicine includes tapping into the knowledge created by networks of engaged patients” | Easily navigated website with tutorials  |