



Putting Patients First: IVI Launches Patient Advisory Council

Seven High-Profile Patient Engagement Leaders to Advise Nonprofit on its Patient-Focused Research Agenda

May 6, 2020 – Alexandria, VA -- The [Innovation and Value Initiative](#) (IVI), a research-based nonprofit improving the science and practice of value assessment, today announced the appointment of seven members to its Patient Advisory Council, an advisory body designed to ensure the patient always remains at the forefront of value assessment.

The Council, which advises the IVI Board of Directors, was envisioned as part of IVI's [patient principles](#) when the organization was established in 2017. Chartered to ensure the organization remains patient focused and transparent, the Council will inform IVI research, strategy, methods and priorities, and support the non-profit organization's patient engagement efforts.

"We know that the status quo—how we do value assessment today—doesn't have the patient front and center; we don't factor in the issues most important to real people when we assess the value of treatment," said Jennifer Bright, Executive Director of IVI. "This is how we actively work to change that."

The Council is comprised of high-profile leaders with deep experience in patient engagement. The seven members of the Council are:

- Alan Balch, PhD, CEO, Patient Advocate Foundation
- Donna Cryer, JD, President & CEO, Global Liver Institute
- Anna Hyde, Vice President of Advocacy and Access, Arthritis Foundation
- Annie Kennedy, Chief of Policy and Advocacy, EveryLife Foundation for Rare Diseases
- Eleanor Perfetto, Executive Vice President, Strategic Initiatives, National Health Council
- Jeanne Regnante, Chief Health Equity and Diversity Officer, LUNgevity
- Leslie Ritter, Associate Vice President, Federal Government Relations, The National Multiple Sclerosis Society

"Since the organization's inception, IVI has put patients first in asking questions about what and how we calculate or assess the value of treatment options," said Alan Balch, CEO of the Patient Advocate Foundation and IVI Board member. "I'm thrilled the Patient Advisory Council has come together and look forward to this collective input as IVI continues to explore and invest in research that puts patient perspectives at the forefront of value assessment models, while also improving healthcare decision makers' understanding of health outcomes that matter most to patient lives."

Patient organizations have contributed to the development of IVI's first two disease-specific models examining value in rheumatoid arthritis and non-small cell lung cancer treatments. Organizations and patients provided critical methodological review, made important recommendations and suggestions, and worked closely with IVI researchers in the development of value tools.

"Today's value assessment models neglect a myriad of elements and factors critical to the people who actually take a medication or experience a therapy, such as data about side effects, preferred outcomes, or burden on caregivers. Thus we end up with models that assign a value to a treatment devoid of useful information to patients. It is time we change so that this math has meaning," said Donna Cryer, President & CEO, Global Liver Institute and IVI Board member.

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