IVI

EQUITY
TRANSPARENCY
PATIENT-CENTRICITY

ANNUAL REPORT

2025

www.valueresearch.org

A Message from Our Leadership

2025 was a pivotal year for IVI.

Amid significant organizational transition, IVI remained focused on its mission and continued to advance the research, partnerships, and multi-stakeholder collaboration that have long been central to our work. Thanks to the commitment of our Board of Directors, members, staff, sponsors, and partners, we ended the year with a strong foundation for what comes next.

Today, IVI is entering a new chapter at an important moment for healthcare. Questions about affordability, access, innovation, and value are increasingly shaping healthcare policy and decision-making. Yet too often, these conversations begin with what healthcare should cost rather than what it should deliver for patients, families, and society.

IVI has an opportunity to help change that conversation.

By bringing together perspectives across research, policy, patient advocacy, industry, and the broader healthcare community, we can advance rigorous research, inform policy, and develop practical approaches that better reflect what matters most to patients and families.

The work highlighted in this report represents both what IVI accomplished in 2025 and the foundation we are building upon. As we look ahead, we do so with greater focus, a clear sense of purpose, and ambition for the role IVI can play in shaping a healthcare system that delivers meaningful value for patients and families.

Thank you for being part of this work and IVI's next chapter.

Marc Boutin
President & Chief Executive Officer

About Us

IVI is an independent nonprofit organization driving the transformation of U.S. healthcare toward a system that defines and rewards value through a patient- and family-centered lens.

Core Principles

Sustains Authentic Patient-Centricity

Advances Transparency

Supports Health Equity

Supporting Principles

Focuses Value Discussion Across Treatment Interventions

Improves Clinical and Real-World Data

Facilitates Customizable Decision-Making

Adapts to and with Evolving Evidence

Cultivates Modern Methods

Fosters Long-Run Innovation

Research Highlights

Blueprint for Patient-Centered Value Research

IVI continued advancing its Blueprint for Patient-Centered Value Research, a framework designed to expand how value is defined and measured in healthcare decision-making. The Blueprint moves beyond traditional cost-effectiveness models by incorporating patient and whole family health value elements, real-world experience, and broader societal impacts. In 2025, IVI focused on refining methodological approaches and identifying opportunities to apply the framework across research initiatives. This work serves as a foundation for integrating patient and whole family health priorities into value assessment and value-based decision-making.

Rare Disease Initiative

IVI's Rare Disease Initiative (funded by PCORI and Alexion) continued to advance efforts to ensure meaningful patient engagement in rare disease research and value assessment. In 2025, IVI led a multi-stakeholder initiative that included six advisory working group meetings, 11 public comment submissions, and three case studies across sickle cell disease, leukodystrophies, and generalized myasthenia gravis.

Insights from this work informed the development of the Rare Disease Patient Engagement (RDPE) Guidance and Checklist, a practical resource designed to support researchers in incorporating patient perspectives throughout the research process. The initiative raised visibility at national meetings, including ISPOR, the World Orphan Drug Congress, NORD Breakthrough Summit, and the PCORI Annual Meeting.

IVI is continuing capacity-building efforts through dissemination and training, supporting researchers and patient advocacy organizations in applying the checklist to ensure outcomes that matter to patients are consistently included in rare disease research.

Economic Impacts Initiative

Uncovering the True Cost of Healthcare, IVI's Patient-Centered Economic Impacts initiative, continued to explore how healthcare decisions affect patients and families beyond traditional clinical and cost metrics. In 2025, IVI engaged nearly 300 researchers, patients, caregivers, and stakeholders to identify patient-centered economic impacts and explore how to apply the Economic Impacts Framework in practice.

IVI hosted four workshops focused on caregiver impacts, diagnostic delays, stress, and the impacts on education and employment. Insights from these discussions informed the development of related learning reports outlining key considerations for measuring economic impacts from a whole family health perspective.

The initiative raised visibility at ISPOR 2025 and the PCORI Annual Meeting while demonstrating real-world impact, with organizations applying insights from the workshops and learning reports to inform research, strengthen the measurement of economic outcomes, incorporate patient journey mapping, and more meaningfully integrate lived experience into research and policy.

> Economic burdens are health outcomes—not external financial issues—and patient experiences must guide how we measure and respond to them.
>
> – Uncovering the True Cost of Healthcare Workshop Participant

Public Policy

In 2025, IVI expanded its policy engagement to ensure that patient-centered value is reflected in healthcare policy discussions. IVI established the Public Policy Council (PPC), bringing together leaders from industry, academia, patient advocacy, and policy organizations to inform priorities and provide strategic guidance.

IVI submitted six comment letters and sign-ons addressing key issues related to healthcare value and drug pricing reform. IVI also hosted the 2025 Fall Policy Summit, *Centering Patient Values in Drug Policy: Transparency, Value, and Access*.

These efforts support IVI's broader position that healthcare policy should move beyond price comparisons alone and instead reflect the full value of treatments, including patient access, innovation, and real-world outcomes.

> If we don't measure the outcomes that matter to patients, it is not going to influence decisions.
>
> – Marc Boutin, IVI President & CEO

Public Policy Council

The PPC is a cross-sector advisory body established to help advance whole patient health in healthcare policy discussions. The Council brings together experts from industry, academia, patient advocacy, health systems, and policy organizations to provide strategic guidance on IVI's growing policy agenda.

Throughout its inaugural year, the PPC helped shape IVI's policy priorities and reinforced the organization's commitment to maintaining an objective, measured, and patient-centered voice in national healthcare policy conversations. Guided by the Council's expertise, IVI focused on key issues including drug pricing reform, international reference pricing, and the importance of transparency and patient-centricity in federal drug price negotiations.

These efforts strengthened IVI's role as a trusted convener and thought leader in healthcare policy, advancing the organization's position that policy decisions should move beyond price comparisons alone and instead reflect the full value of treatments, including patient access, innovation, and real-world outcomes.

Communications & External Engagement

In 2025, IVI expanded its national presence through strategic communications and outreach efforts designed to increase awareness of whole family health value research. IVI produced four white papers and reports, ten press statements and blogs, and ten thought leadership opportunities, while securing 35 external mentions, including podcasts and interviews.

Social media engagement grew by 28% and IVI executed 64 e-mail campaigns reaching more than 77,400 recipients, contributing to a 22% increase in the organization's master contact list. These efforts helped broaden the reach of IVI's research and strengthen its position as a leading voice in patient and whole family health value assessment.

IVI researchers contributed to several peer-reviewed publications and thought leadership pieces in 2025 that advanced the field of patient-centered value assessment, health technology assessment, and outcomes research.

VALUE IN HEALTH

Patient-Informed Value Elements in Cost-Effectiveness Analyses of Major Depressive Disorder Treatment: A Literature Review and Synthesis

Slejko JF, Mattingly TJ, Wilson A, Xie R, Chapman RH, Amill-Rosario A, dosReis S

This systematic review found that published cost-effectiveness models for MDD treatment rarely reflect what patients actually value or involve patients and caregivers in their development. The authors call for more stakeholder engagement in model development.

https://doi.org/10.1016/j.jval.2024.05.017

VALUE & OUTCOMES SPOTLIGHT

Incorporating Patients in Open-Source Model Development: A Patient-Centered Approach to Health Technology Assessment

Parsley-Raines L, Cheng YYM, Chapman RH

This article describes how a patient-centered approach to health technology assessment builds genuine partnerships with patients, families, and caregivers throughout the process – using their input to shape research questions, expand outcome measures beyond standard metrics, and improve open-source models.

https://www.ispor.org/heor-resources/presentations-database/presentation/intl2024-3895/140081

PHARMACOECONOMICS

HTA Evidence in Rare Diseases: Just Rare or Also Special?

Basu A, Thomas SK, Chapman RH, Spangler J

This paper argues that orphan drug developers face unique HTA hurdles and calls for tailored HTA approaches designed specifically for rare diseases rather than a one-size-fits-all framework. The authors note that using a single HTA framework for both common diseases and rare diseases could hamper scientific innovation and negatively impact patient health and societal well-being.

https://doi.org/10.1007/s40273-025-01538-4

THE AMERICAN JOURNAL OF MANAGED CARE

The Role of Dynamic Pricing in Health Technology Assessment for Major Depressive Disorder

Seo D, Raines L, Chapman RH

In this commentary, the authors argue that building drug price changes into cost-effectiveness models over time ("dynamic pricing") – rather than assuming fixed prices – gives more accurate estimates, which could support more equitable resource allocation and sustainable coverage decisions.

https://www.ajmc.com/view/contributor-the-role-of-dynamic-pricing-in-health-technology-assessment-for-mdd

These publications reflect IVI's commitment to advancing patient-centered value assessment methods, elevating the role of patient perspectives in research, and contributing evidence and thought leadership to inform healthcare decision-making.

Stakeholder Engagement & Convenings

Convening diverse stakeholders remains central to IVI's mission. In 2025, IVI hosted workshops and collaborative discussions bringing together researchers, patients, caregivers, policymakers, and industry leaders to advance patient-centered value research.

> Traditional approaches to value assessment often don't really account for that patient perspective.
>
> – Stacy Lloyd, IVI Chairperson of the Board

6th Annual Methods Summit

In March 2025, IVI hosted its 6th Annual Methods Summit, sponsored by Alexion and Pfizer. With over 300 registrants, the event convened leaders across research, policy, and patient advocacy to explore how value assessment methods can better capture what matters most to patients. Discussions led by our 14 distinguished speakers focused on a comprehensive exploration of patient-centered value research, guiding attendees through every stage – from defining value and engaging patients to implementing and adapting research strategies based on real-time data.

Participants examined how researchers can include patients as co-creators in research, the potential for artificial intelligence to address evidence gaps in rare disease research, and effective ways to communicate research findings to diverse audiences and drive healthcare change. Insights from the Summit continue to inform IVI's research agenda and contribute to national conversations on evolving methods for value assessment.

2025 Fall Policy Summit

IVI's 2025 Fall Policy Summit brought together leaders from government, academia, patient advocacy, and industry to explore policy solutions that better incorporate whole family health into healthcare decision-making. The full-day hybrid event attracted more than 280 registrants and fostered cross-sector dialogue on the future of drug pricing reform and patient-centered healthcare policy.

Discussions focused on the limitations of relying solely on international price comparisons to inform U.S. drug pricing policy. Speakers emphasized that meaningful reform must balance affordability, access, and continued innovation while keeping patient outcomes at the center of decision-making. Participants also highlighted the importance of integrating patient and caregiver perspectives throughout the policy development process to ensure reforms reflect the real-world experiences and needs of those most affected.

Key themes emerging from the Summit included the complexity of comparing healthcare systems across countries, the potential unintended consequences of policies such as international reference pricing and "most favored nation" approaches, and the need to move beyond price alone as the primary measure of value. Discussions underscored that a whole family health approach to value assessment can support a more sustainable, equitable, and innovation-friendly healthcare system while preserving access to current and future treatments.

The Summit was made possible through the generous support from our sponsors: Arthritis Foundation, Canary Advisors, Dravet Syndrome Foundation, AiArthritis, International Pemphigus & Pemphigoid Foundation (IPPF), Johnson & Johnson, National Health Council, Sick Cells, South Asian IBD Alliance, and Takeda.

Financial Overview

	Without Donor Restrictions	With Donor Restrictions	Total
Support and Revenue			
Membership Dues	$ 503,000	$ 202,500	$ 705,500
Grants	$ 101,958		$ 101,958
Contract Revenue	$ 781,916		$ 781,916
Investment Income	$ 24,978		$ 24,978
Other Income	$ 388,333	$ (388,333)	
Net Assets Released from Restrictions	$ 1,800,185	$ (185,833)	$ 1,614,352
Expenses			
Program			
Research Projects	$ 756,794		$ 756,794
Stakeholder & Patient Engagement	$ 141,740		$ 141,740
Media Communications	$ 258,380		$ 258,380
Membership	$ 216,214		$ 216,214
Total Program Expenses	$ 1,373,128		$ 1,373,128
Supporting Services			
General & Administrative	$ 370,425		$ 370,425
Fundraising	$ 80,363		$ 80,363
Total Supporting Services	$ 450,788		$ 450,788
Total Expenses	$ 1,823,916		$ 1,823,916
Item	**Amount**		
Change in Net Assets	$ (23,731)	$ (185,833)	$ (209,564)
Net Assets, Beginning of Year	$ 328,553	$ 388,333	$ 716,886
Prior Period Adjustment	$ (57,360)		$ (57,360)
Net Assets, Beginning of Year, Restated	$ 271,193	$ 388,333	$ 659,526
Net Assets, End of Year	$ 247,462	$ 202,500	$ 449,962

2025 Membership

IVI's membership unites diverse stakeholders, researchers, patient advocates, healthcare organizations, life sciences companies, and policy leaders, all committed to advancing patient-centered healthcare. Members engage in research, contribute expertise, and participate in convenings and advisory councils to shape methodologies and policies.

abbvie

AcademyHealth

AMCP Academy of Managed Care Pharmacy®

AiARTHRITIS International Foundation for Autoimmune & Autoinflammatory Arthritis

ALEXION AstraZeneca Rare Disease

Alliance for Aging Research

American Brain Coalition

Arthritis Foundation®

The Assistance Fund

Boehringer Ingelheim

Bristol Myers Squibb

Coalition of Skin Diseases

DiME Digital Medicine Society

Dravet Syndrome Foundation

EBRI Employee Benefit Research Institute

EveryLife Foundation for Rare Diseases

FSR Foundation for Sarcoidosis Research

IfPA Institute for Patient Access

International Rett Syndrome Foundation

ippf International Pemphigus & Pemphigoid Foundation

Johnson&Johnson

Lilly

MedStar Health

MERCK

National Alliance of Healthcare Purchaser Coalitions Driving Health, Equity and Value

National Eczema Association

National Health Council

NORD® National Organization for Rare Disorders

NPAF National Patient Advocate Foundation The Patient's Voice | since 1996

National Pharmaceutical Council®

Neurotech Network

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PIPC Partnership to Improve Patient Care

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2025 IVI Team

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Rick Chapman
Chief Science Officer

Michelle Cheng
Research Manager

Tiffany Huth
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Lisa Malecha
Chief Finance Officer

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Ushma Patel
Director of Patient Engagement

Larragem Raines
Director of Research

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Chief Program & Development Officer

Smita Sanwardeker
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Sarah Daugherty, Carelon Research
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Michael Johnsrud, Texas Center for Health Outcomes Research and Education
Adrian Kielhorn, Alexion, the Rare Disease Division of Astra Zeneca
Tara Lavelle, Tufts University School of Medicin
Russ Montgomery, GSK
Cheryl Neslusan, Janssen Scientific Affairs, Johnson & Johnson
Surachat Ngorsuraches, Auburn University
Debbie Smith, UCB, Inc.
Claire Telford, Pfizer
Daniel Touchette, University of Illinois Chicago

Patient Advisory Council

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Desiree Collins-Bradley, Patient Partner Innovation Community
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Danny van Leuwen, Health Hats
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Adam Thompson, Plain Speak Consulting
Joseph Washington, Independent Consultant
Tiffany Westrich-Robertson, AiArthritis

Public Policy Council

Nitzan Arad, Duke-Margolis Institute for Health Policy
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Fauzea Hussain, McKesson
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Richie Kahn, Canary Advisors
Claire Sachs, TPAC Consulting
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Lisa Feng, Bristol Myers Squibb

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