

2023

Annual Report





Grounded in the principles of patient-centricity, transparency, and equity, **IVI** is a leader in the health technology assessment and healthcare community.

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+ 2023 AT A GLANCE

82%

of total revenue goes
toward research

17

new members

\$1.85M

total research
spending

200+

participants at the 2023
Methods Summit

Message from the CEO

2023 was a transformative year for the Innovation and Value Initiative (IVI).



Jason Spangler, MD,
MPH, FACPM
Chief Executive Officer

Our community's collaborative spirit and dedication drove health technology assessment (HTA) and patient-centered research advancements. Reconnecting with our members, colleagues, and team in person underscored the value of our collective efforts.

Our Annual Report includes a financial audit, key milestones, and significant accomplishments across all facets of the organization. Together with our members and partners, we worked diligently to benefit all patients and advance the field of HTA. Our strong financial performance in 2023 enabled increased investments in research, convenings, operations, and outreach. We welcomed two additional staff members and proudly launched new initiatives in our research portfolio.

Economic Impacts on Patients and Caregivers (Phase 1): This project provides guidance on incorporating the full range of economic impacts on patients and caregivers into comparative effectiveness research and patient-centered HTA.

Value in Rare Disease (Phase 1): This initiative explores new methodologies to better understand and measure patient-centered outcomes in rare diseases, aiming to improve HTA approaches for these conditions.

Health Equity Initiative: Committed to embedding health equity across our projects, this initiative catalyzes action towards developing HTA methods that promote equitable health access and outcomes through research, education, and stakeholder engagement.

Disparities in Youth MDD Care Claims Analysis: This analysis examines the disparities in care for youth with major depressive disorder (MDD), providing insights to inform more equitable health policies and practices.

IVI-MDD Value Model (Beta Launch): We are thrilled to introduce the beta version of our Major Depressive Disorder Open-Source Value Model, a tool designed to enhance the evaluation of MDD treatments through a patient-centered lens.

Patient-Driven Priorities for MDD Management DCE: This discrete choice experiment identifies patient-driven priorities in the management of MDD, ensuring that patient preferences are central to treatment and policy decisions.

Valuing Innovation Project Call for Papers and Award Recipients: As part of our multi-phase initiative to advance the dialogue on HTA, we launched a call for papers to identify gaps and build consensus on practical methods for measuring and rewarding innovation. We also celebrated the award recipients who have contributed valuable insights to this effort.

At IVI, collaboration and stakeholder engagement are essential to our work. The dedication and support of everyone who participated in our events this year have been crucial in achieving our goals.

In 2024, we plan to advance Phase II of the Economic Impacts on Patients and Caregivers and the Value in Rare Disease initiatives. We will also expand our Health Equity Program and explore its research applications through various use cases.

As we reflect on 2023, we are grateful for the dedication and enthusiasm of our members. Your contributions have been crucial to our achievements, and the commitment and expertise of our talented team have been key to our success. IVI is well-positioned to have an even greater impact on patients' lives and the future of HTA in 2024 and beyond.



“How do you take the entirety of a person and their life journey into one bucket?

You can't group a 17-year-old and an 80-year-old and expect them to have the same economic impacts, even if they have the same disease.”

– Economic Impacts Roundtable Participant

Patient-Centricity & Equity

Health Equity Initiative

In 2023, IVI concluded its two-year Health Equity Initiative, engaging over 245 stakeholders from various sectors, including patients, caregivers, researchers, payers, employers, and healthcare providers, to improve health equity in Health Technology Assessment (HTA) in the United States.

The initiative produced two key reports:

[No Value Without Equity: Transforming Practice and Accountability for Equity in Health Technology Assessment](#). This synthesis report presents IVI's Framework for Centering Equity in HTA.

[Fulfilling the Promise of Equity in Value-Based Care: A Focus on Power, People, and Processes in Health Technology Assessment](#). This report explores four foundational changes in HTA related to "Power, People, and Processes" to enhance equity, emphasizing:

- Partnering with patients and caregivers in co-leading and co-creating HTA.
- Prioritizing representation from marginalized communities.
- Recognizing contributions from patients and caregivers.
- Ensuring a diverse HTA workforce.

IVI extends its gratitude to the [Health Equity Initiative Steering Committee](#) for their guidance and support.



“How can HTA be considered reliable and valid if it is not representative?”

— Equity Key Informant Interview Participant

Economic Impacts on Patients and Caregivers

In 2023, IVI completed Phase I of the Economic Impacts Project. Partnering with AcademyHealth and over 160 stakeholders, IVI developed a framework to help researchers and decision-makers understand the full range of economic impacts on patients, caregivers, and family members. This project resulted in poster presentations at ISPOR 2023, Academy Health's ARM Conference, and PCORI's 2023 Annual Meeting.

Participants identified six main areas of economic impacts: direct medical costs, non-clinical healthcare costs, caregiver and family impacts, social impacts, ability to work, and education and job impacts.

Economic Impact Framework

The first and most important consideration for applying the framework is to center the experiences of patients and caregivers, engaging them authentically in the research process from the beginning.

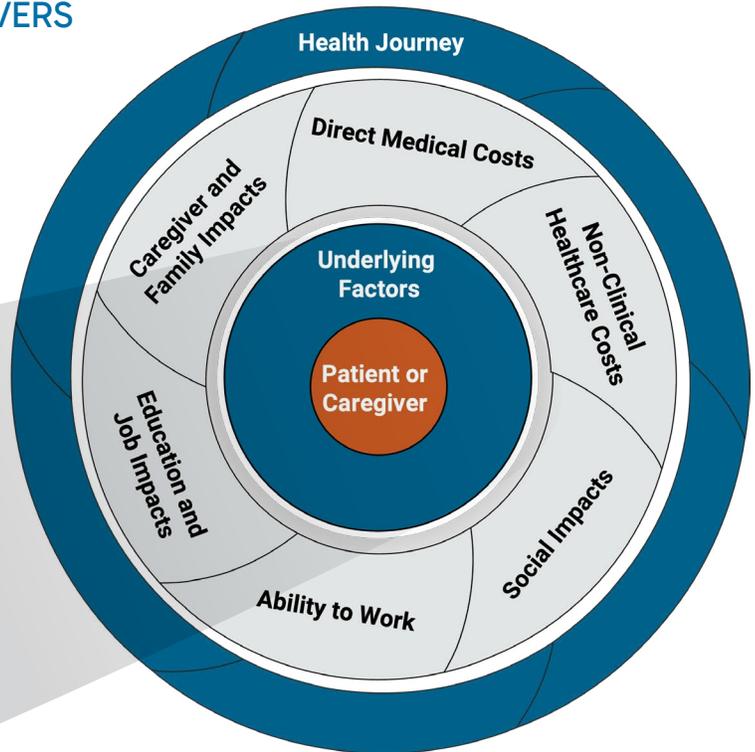
Phase II of the project will begin in March 2024. The framework was funded by a Eugene Washington PCORI Engagement Award (EASCS-24274) and membership contributions. You can find the full report [here](#).

FRAMEWORK TO UNDERSTAND ECONOMIC IMPACTS ON PATIENTS AND CAREGIVERS

Underlying Equity Factors Central to a Patient's Health Journey and Economic Impacts

- A. Health Needs and Complexity
- B. Changes in Health Status and Economic Impacts over Time
- C. Social Drivers of Health
- D. Life Stage
- E. Access to or Gaps in Care
- F. Time to Diagnosis
- G. Socioeconomic Status

We use the term "patient" with the understanding that he or she is a full person and should not be defined by their health condition.



Rare Disease Initiative

In 2023, IVI partnered with the EveryLife Foundation for Rare Diseases on a year-long initiative to identify key themes and recommendations for incorporating patient-centered outcomes into comparative effectiveness research for rare diseases. A 15-person multi-stakeholder steering committee guided the project. Three roundtable discussions focused on:

- Identifying significant outcomes for rare disease patients and caregivers
- Fostering communication between payer and patient stakeholders
- Reaching a consensus on recommendations to enhance patient-centered outcomes research

Key themes included:

- Patient journey and time
- Caregiver journey
- Early and continuing engagement and communication
- Data and methods
- Economic impacts
- Scientific spillover
- Identifying common patient-centered outcomes for economic modeling

IVI and the EveryLife Foundation explored the critical role of patient-centered outcomes and health technology assessment (HTA) in advancing rare disease therapy during a webinar featuring experts and stakeholders, discussing groundbreaking insights and patient-centered research.



Patient-Driven Priorities for Management of MDD

IVI partnered with the PAVE Center of the University of Maryland to conduct a discrete choice experiment to assess patient-informed preferences for major depressive disorder treatment.

A representative sample of 300 individuals living with MDD were surveyed to understand their priorities in managing the disease and how that might be influenced by race and ethnicity, income, productivity loss, and geographic area. A literature review of patient-informed value elements included in prior MDD economic models was also conducted to inform this work.

Results from the completed survey and literature review were presented via two posters and a presentation at the ISPOR 2023 annual conference and have been submitted for publication. IVI is collaborating with an expert working group to identify ways to incorporate these patient preference data into the MCDA module of the IVI-MDD Value Model.



Advancing Methods and Practice of HTA

Valuing Innovation Project

IVI held its first call for papers in 2023, as part of our Valuing Innovation Project. Innovations in health technologies have been a major contributor to improved life expectancy and quality of life, but methods to define and measure innovation in HTA have not kept pace. Our call for papers sought innovative ideas to address research questions prioritized from cross-stakeholder discussions at IVI's 2022 Methods Summit and an expert roundtable:

- How do we better define, measure, and reward **scientific spillovers** in HTA?
- How do we better define, measure, and reward **real option value** in HTA?
- How can HTA better account for the **impacts of innovation on broader society beyond the healthcare sector**?

The winners can be viewed [here](#). Their papers are currently undergoing peer review for publication in 2024. We look forward to seeing these methods put into practice as we strive to measure innovation in HTA.

Multi-Criteria Decision Analysis (MCDA) Module for the IVI-MDD Value Model

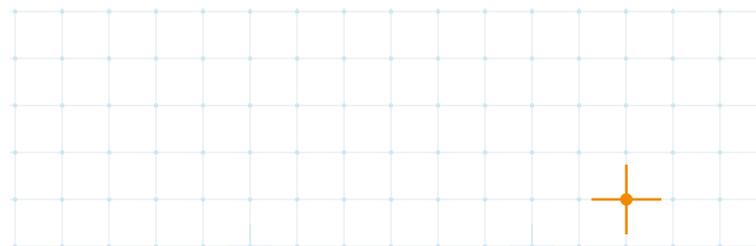
Reflecting IVI's commitment to innovation in HTA, the IVI-MDD model will also feature a multi-criteria decision analysis (MCDA) module. MCDA provides an alternative to cost-effectiveness analysis allowing users to consider a wider range of criteria than most economic analyses, including qualitative inputs from patients. We have partnered with an expert working group to determine appropriate techniques for incorporating the MCDA procedure into the model and in 2023 identified the set of attributes that can be selected for use in the MCDA. We are currently consulting with the expert working group to specify appropriate procedures for weighting and scoring these defined attributes. The development of the MCDA module will be completed in 2024.

Major Depressive Disorder Value Model

In 2023, IVI reached a major milestone in our multi-year project to develop an open-source economic model for treatments of [major depressive disorder \(MDD\)](#), releasing the model publicly in September. This achievement followed extensive stakeholder engagement from the initial planning stages, with ongoing input from a multi-stakeholder Advisory Group and discussions with clinical and technical experts. Advisors included individuals with lived experience of MDD, clinicians, health economists, payers, purchasers, and researchers, providing guidance on the model's development and dissemination.

We conducted interviews with potential users to refine the model's user interface, ensuring it was relevant to various perspectives and included patient-centered outcomes. Upon launch, we solicited feedback from early users on the model structure and interface, gathering recommendations for improvement. IVI is currently revising the model and planning several applications to demonstrate its utility and versatility. We will continue to integrate stakeholders' perspectives and priorities to ensure the model remains a credible and transparent decision-making tool for evaluating MDD treatments.

IVI also hosted a [webinar](#) to discuss the purpose and background of the project, areas where IVI is seeking input, and a demonstration of the model. The webinar covered technical aspects, challenges, the rationale for the model structure, and provided a preview of planned research projects.



Convenings

2023 Methods Summit

Rewriting the Playbook on Health Technology Assessment: Equity and Economic Impacts on Patients and Families

In March, IVI convened its fourth Annual Methods Summit, a two-day event dedicated to identifying practical actions to move towards health equity and true value in health technology assessment. With over 226 attendees at this virtual and in-person event, the Methods Summit served as a culmination of the first year of IVI's Health Equity Initiative and an important inflection point for the Economic Impacts Project.

Keynote speakers included:

- Dora Hughes, MD, MPH, Chief Medical Officer, CMS Innovation Center, Centers for Medicare & Medicaid Services
- Nakela L. Cook, MD, MPH Executive Director, PCORI
- Donna Cryer, JD, CEO, Global Liver Institute

Themes included:

- Pursue Fundamental Change
- Shift To Shared Power With Patients And Families
- Prioritize Redefining Data
- Practice Transparent, Accessible Communication
- Emphasize Shared Learning And Continuous Improvement
- Establish Accountability For Change And Measure Progress

Throughout the two-day event, speakers and participants stressed the need to move beyond merely discussing health equity and considering economic impacts. They highlighted the importance of taking meaningful action to adjust processes and methods in HTA to fully account for health equity.

For the full proceedings, please go [here](#).



Annual Meeting

IVI's 2023 Annual Meeting featured research initiatives including the IVI Major Depressive Disorder (MDD) Value Model, rare diseases, and economic impacts. Throughout the day, three themes rose to the top:

- Start with the patient and caregiver.
- Collaboration is key.
- Health equity is not just a sideshow, it is the main event.

These themes underscore the need for better data that reflects the experiences and priorities of patients and caregivers. While the lack of data won't hinder progress, it's important to recognize the limitations of any assessment. These discussions remind us that the healthcare system is evolving. With the Inflation Reduction Act and the rapid growth of new treatments, it's essential to ensure patients remain at the center of the health system through continuous communication and collaboration.

“Equity does not affect only certain population cohorts. It affects all of us, either in the moment, or in the future.”

— Gretchen Wartman,
National Minority Quality Forum



IRA & Equity Symposium

On December 5, 2023, the Innovation and Value Initiative (IVI), the Alliance for Aging Research, the National Pharmaceutical Council, and Leavitt Partners, LLC, organized a half-day symposium in Washington, D.C., titled “Ensuring Equity in Implementation of IRA Drug Price Negotiations.” The event focused on equity and patient and family engagement in the implementation of the Drug Price Negotiations Program (DPNP) in the Inflation Reduction Act (IRA) by the Centers for Medicare & Medicaid Services (CMS).

The symposium brought together diverse perspectives, including patients, patient advocacy groups, quality measurement experts, government agencies, the biopharmaceutical industry, and academia, aiming to identify actionable recommendations for CMS leadership and staff. The discussions highlighted the importance of CMS demonstrating leadership in advancing equity and inclusion despite the complexities and challenges.

Key elements of a successful equity-centered approach discussed included:

- A robust patient and caregiver engagement program similar to the FDA's patient affairs program
- Open and explicit communication with patients and stakeholders throughout the process
- Continuous equity-focused quality measurement, evaluation, and improvement

The symposium underscored the critical need for CMS to commit both philosophically and materially to a collaborative, equity-centered implementation approach, particularly in the Drug Price Negotiation Program.

Communications

Over the past year, IVI has released original content and news, which provide updates and insights into Health Technology Assessment (HTA) and how value is assessed in healthcare.

Our content and marketing strategy is a platform to elevate the organization's thought leadership, research prowess, and collaborative initiatives via an integrated channel approach. This strategy encompasses earned, owned, and social media content as conduits for distribution, leveraging established media relationships and collaborators to amplify visibility.

IVI remains committed to crafting purposeful communications and messaging to strengthen our brand while emphasizing the pivotal role of patient-centricity in HTA. Moreover, our research portfolio experiences steady growth and diversification, yielding publications, posters, and reports in collaboration with partners, thus substantiating the transparent execution of patient-centered HTA while opening up increased earned media opportunities and enhanced visibility.



Optum: Let's Talk Value Assessment

Let's Talk, a series from Optum Life Sciences, aims to feature thought-provoking insights and discussions that capture what's on the minds of life science leaders. Optum featured IVI CEO Jason Spangler, spotlighting how IVI defines value in healthcare and aims to shape CMS's approach to evaluating medical value during negotiations with drug manufacturers.



The Evidence Base

In his guest column for The Evidence Base, Jason Spangler discussed the impact of the IRA on the healthcare landscape in the US. He explained how this landmark legislation could affect drug development and patients.

26

Press Statements

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Blog Posts & Member Spotlights

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External Mentions, Podcasts & Interviews

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Thought Leadership Opportunities

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Commentaries/ White Papers



ISPOR

The ISPOR Annual Conference was a great opportunity for IVI's staff to connect with other professionals in the industry. The team was able to participate in pivotal discussions, share their knowledge and expertise, and raise awareness of IVI's work. Over the course of the conference, IVI was involved in several events that allowed them to showcase their research and engage with attendees in a meaningful way. IVI participated in two workshops, one issue panel, nine posters and one podium presentation, and hosted a networking social happy hour.



HealthEconomics.com

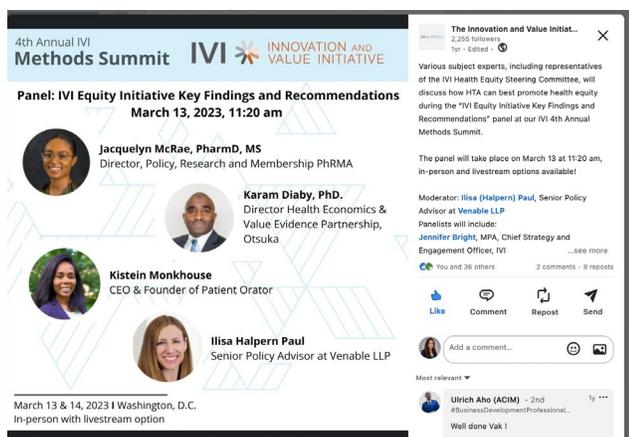
IVI Chief Science Officer, Rick Chapman, PhD, was a featured speaker in a webinar titled "Finding Value in Linking Real-World Data with Social Determinants of Health." The webinar was sponsored by Magnolia Market Access. During the webinar, Chapman discussed multiple approaches to improve patient health outcomes and promote health equity.

77%
Social Media Growth

1,750
LinkedIn Followers

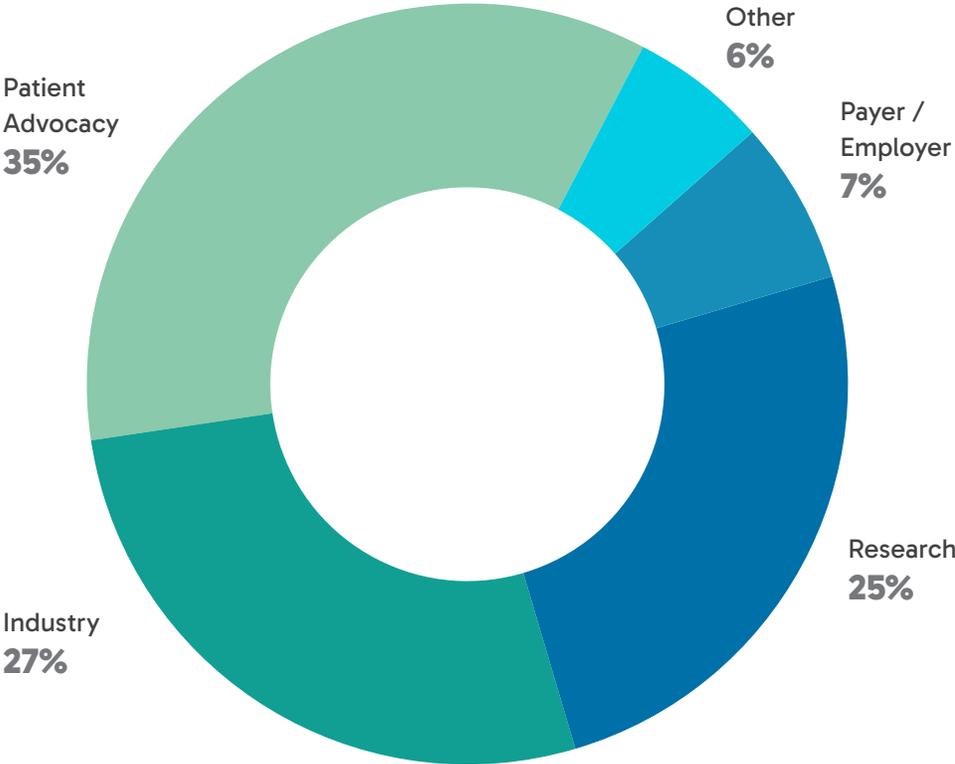
100+
LinkedIn Posts

Social Media



Membership

By Audience



16%

YEAR-OVER-YEAR
MEMBERSHIP GROWTH

Financials

Statement of Activities for the year ended December 31, 2023

	Without donor restrictions	With donor restrictions	Total
Support and revenue			
Membership dues	\$ 1,787,592	\$ 536,583	\$ 2,324,175
Grants	426,851	-	426,851
Contract revenue	115,450	-	115,450
In-kind contribution	10,000	-	10,000
Investment income	23,754	-	23,754
Net assets released from restrictions	335,925	(335,925)	-
	<u>2,699,572</u>	<u>200,658</u>	<u>2,900,230</u>
Expenses			
Program			
Research projects	1,849,027	-	1,849,027
Stakeholder and patient engagement	232,951	-	232,951
Media communications	408,668	-	408,668
Memberships	143,777	-	143,777
	<u>2,634,423</u>	<u>-</u>	<u>2,634,423</u>
Supporting services			
General and administrative	508,989	-	508,989
Fundraising	62,811	-	62,811
	<u>3,206,223</u>	<u>-</u>	<u>3,206,223</u>
Change in net assets	(506,651)	200,658	(305,993)
Net assets, beginning of year	1,298,320	335,925	1,634,245
Net assets, end of year	<u>\$ 791,669</u>	<u>\$ 536,583</u>	<u>\$ 1,328,252</u>

2023 BOARD OF DIRECTORS



Michael Thompson
President
National Alliance of
Healthcare Purchaser
Coalitions



Mark Cziraky, PharmD
President-Elect
HealthCore (currently
Carelson Research)



Greg Daniel, PhD
Past President
Eli Lilly



Patty Fritz, MA
Secretary/Treasurer
UCB, Inc.



Alan Balch, PhD
Patient Advocate
Foundation



John Banta, MBA, BS
Blue Cross Blue Shield
Venture Partners,
Blue Cross Blue Shield
Association



Harold Carter, PharmD
Express Scripts



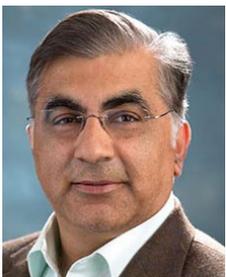
Charles Cutler, MD, MS
Cutler Healthcare



Nelly Ganesan, MPH
JP Morgan Chase & Co.,
Morgan Health



Suzanne Schrandt
ExpPect Consulting



**Vipin Sood, MBA, RPh,
MRPharmS**
Consultant



Adam Thompson, MPH
Consultant



Ashley Valentine, MRes
Sick Cells



Neil Weissman, MD
MedStar Health
Research Institute

2023 MEMBERS

Innovators Circle

Biotechnology Innovation Organization
Bristol Myers Squibb
GSK
Janssen Scientific Affairs
(currently Johnson & Johnson
Innovative Medicines)
National Pharmaceutical Council
PhRMA
Takeda
UCB, Inc.

Large Organization

AbbVie
Alexion, AstraZeneca Rare Disease
Amgen
Edwards Lifesciences
Eli Lilly
Genentech
Gilead Sciences
Novartis
Otsuka US
Pfizer
Sage Therapeutics

Large Nonprofit

Academy of Managed Care Pharmacy
Arthritis Foundation
BCBS Venture Partners
Everylife Foundation for Rare Diseases
MedStar Health Research Institute
The Assistance Fund

Small Nonprofit

AcademyHealth
Alliance for Aging Research
Coalition of Skin Diseases
Institute for Patient Access
International Foundation for
Autoimmune & Autoinflammatory
Arthritis (Ai Arthritis)
International Rett Syndrome
Foundation
National Alliance of Healthcare
Purchaser Coalitions
National Health Council
National Patient Advocate Foundation
Network for Excellence in Health
Innovation
Partnership to Improve Patient Care
Patients Rising
Sick Cells
SynGap Research Fund
Haystack Project
Neurotech Network

Individual Academic

Anton Avanceña
Juan Marcos González Sepúlveda
Bruny Kenou
Olivia Lubarsky
Leticia Moczygamba
Tan Nguyen
Sherry Wang

Individual Advocate/ Nonprofit

Rachel Patterson
Suz Schrandt
Richard Seiden
Josh Trent
Danny van Leeuwen
Claire Sachs
Maureen Hensley-Quinn
Elridge Proctor
Gretchen Wartman

Individual Affiliate

Kirsten Beronio
Harold Carter
Mark Cziraky
Nelly Ganesan
Lou Garrison
Laura Pizzi
Vipan Sood
Adam Thompson
Cristie Travis
Kimberly Westrich

2023 IVI STAFF



**Jason Spangler, MD,
MPH, FACPM**
Chief Executive Officer



Jennifer Bright, MPA
Chief Strategy and
Engagement Officer



Jessica Brown
Membership and
Marketing Manager



Rick Chapman, PhD
Chief Science Officer



Michelle Cheng, MHS
Research Manager



Tiffany Huth, MPH
Chief Communications
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Mark Linthicum, MPP
Director of Policy



Lisa Malecha, MBA
Chief Financial Officer



Erica de Fur Malik
Chief Operating Officer



Ushma Patel, MPSH, PMP
Director of Patient
Engagement



Larragem Raines, MS
Director of Research



Melanie Ridley
Chief Program &
Development Officer



Smita Sanwardeker, MS
Communications Manager



Judy Thomas
Administrative Assistant



Richard Xie, PhD
Director of Research

IVI  INNOVATION AND
VALUE INITIATIVE

www.thevalueinitiative.org