DYNAMIC GLOBAL EVENTS

JANUARY 27–28, 2026
SAN DIEGO, CA

2ND CHIEF PATIENT OFFICER SUMMIT – WEST

Empowering Leaders of Engagement, Advocacy, Communications and Support Services to Reflect the Patient Experience in Every Stage of Operations

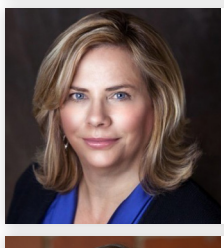
FEATURED SPEAKERS

Thomas Bartle
National Patient Ambassador, Research and MG Registry
MGFA

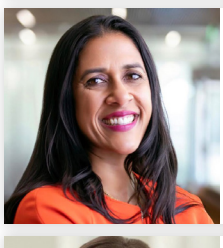
Anna Berkenblit
Chief Scientific & Medical Officer
PANCREATIC CANCER ACTION NETWORK

Anne Bruns
Executive Director, Patient Engagement, Neurology
PTC THERAPEUTICS

Shannon Callison
Senior Clinical Trial Manager
ENTRADA THERAPEUTICS

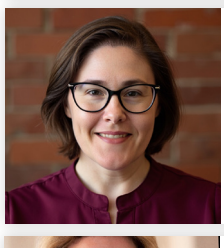


Mindy Cameron
Patient Engagement Consultant
ADVOCACY WORKS



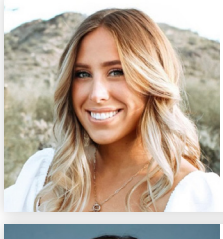
Sonali Chopra
Head, Patient Advocacy Relations
GENENTECH

Ryan Cliche
Executive Director
BREAST360 FOUNDATION



Devra Densmore
CEO & Principal
ELEVATE ADVOCACY

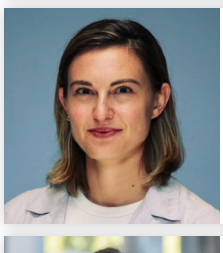
Sarah Friedhoff
Head of Patient Advocacy
ENTRADA THERAPEUTICS



Sydney Gardner
Senior Manager, Patient Advocacy
DENALI THERAPEUTICS

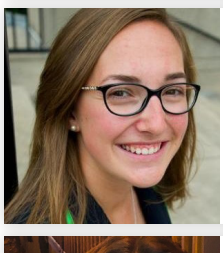
Amy Grover
Executive Director of Patient Advocacy
CATALYST PHARMACEUTICALS

Roya Hakimzadeh
Director, Patient Advocacy
BLOOM SCIENCE



Cara Hunt
Senior Patient Advocacy Operations Specialist
CYTOKINETICS

Catherine Jackson
Senior Director, Patient Engagement and Advocacy
MALLINCKRODT PHARMACEUTICALS



Danielle Jordan
Director, Marketing
ARDELYX

Molly Keane
Senior Manager Patient Advocacy
AMGEN

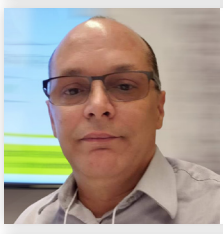
Jin Lee
CEO
IMIDEOLOGY

Anita Longoria
Patient Advocate
MYASTHENIA GRAVIS SUPPORT GROUP

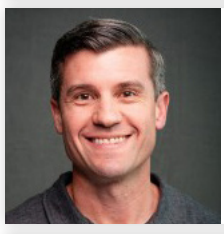
Matt Nestor
Vice President, Development Strategy and Partnerships
PARTNER THERAPEUTICS

Jasmine Patel
Director, Patient Advocacy
EDGEWISE THERAPEUTICS

Johannah Ruddy
Senior Director of Patient Advocacy
ARDELYX



Frank Rivera
President
STRONGER THAN SARCOIDOSIS

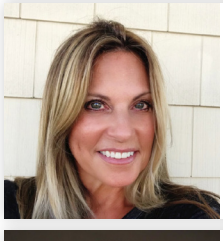


J.P Sacksteder
Senior Director, Advocacy Relations
GENENTECH

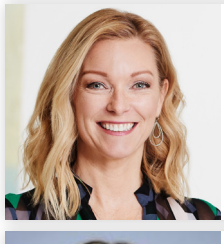
Fatima Scipione
Vice President, Global Patient Affairs
BLUEPRINT MEDICINES

Alycia Shilton-Lloyd
Executive Director, Hematology-Oncology, Patient Innovation & Engagement, Value & Implementation
MERCK

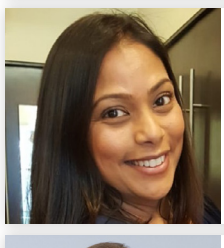
Sandra Shpilberg
Co-founder & COO
ADNEXI



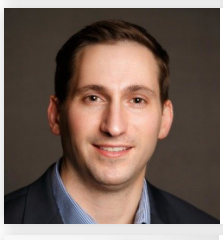
Susan Stein
US Patient Advocacy Lead
ZAMBON GROUP



Amy Akers Teets
Global Head Patient Strategy, Specialty Care
SANOFI



Naziah Lasi-Tejani
Global Patient Partnership Group Leader, Hematology/ Oncology
ROCHE



Steven Unger
Senior Director, Patient Experience
BRISTOL MYERS SQUIBB

Vera Toth-Fejel
Sr. Director, Patient Advocacy
GOSSAMER BIO

Tiffany Valentine
Associate Director Patient Engagement, Global Purpose & Patient Experience, Corporate Affairs
BRISTOL MYERS SQUIBB

Teonna Woolford
CEO
SICKLE CELL REPRODUCTIVE HEALTH EDUCATION DRIVE

ALL NEW SESSIONS

- Crossroads of Advocacy: Legacy, Influence, and the Future of Patient Voice
- Transform Rare Disease Care Through Applied Technologies, Data, and Media
- Elevate the Patient Voice: Co-Authoring Publications with Patients at the Forefront
- Navigate Health Equity and Healthcare Access Amid New Policy Shifts
- Partner with Patient Advocacy Groups: Strategies for Compliance and Impact

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2ND CHIEF PATIENT OFFICER SUMMIT – WEST

Empowering Leaders of Engagement, Advocacy, Communications and Support Services to Reflect the Patient Experience in Every Stage of Operations

Patient advocacy is the cornerstone of building trust and collaboration between patients, industry, and healthcare providers. Getting the best results from patient advocacy requires strengthening cross functional collaboration, elevating the patient voice, and communicating the value of advocacy company wide. Are you prepared to explore the strategies that will take your patient advocacy initiatives to the next level?

DGE invites you to San Diego on January 27–28, 2026 for uniquely detailed and insightful discussions on how to elevate patient voices in clinical development, drive impactful partnerships, and MUCH more!

WHO WILL ATTEND

- Advocacy
- Engagement
- Patient Affairs
- Public Affairs
- Medical Affairs
- Clinical Operations
- Clinical Trials
- Experience
- Support Services
- Adherence
- Communications
- Patient Centricity
- Digital Engagement
- Education
- Access
- Patient Assistance Programs
- Rare Disease
- Disease Awareness
- Government Affairs
- Diversity and Inclusion

REGISTER

DAY ONE

Tuesday, January 27th , 2026

ALL TIMES ARE IN PST

8:00 AM	**Registration & Networking Breakfast**
8:45 AM	**Chairperson's Opening Remarks** Fatima Scipione, Vice President, Global Patient Affairs, **BLUEPRINT MEDICINES**
9:00 AM	**Communicate the Value of Patient Advocacy to Senior Leadership**

When showcasing the impact of patient advocacy, it's essential to highlight measurable outcomes. The key question is: how are we defining and measuring success? Is success reflected in the growth and evolution of the advocacy community itself? In the ability of patients to engage meaningfully with care teams? In their improved understanding of, and ability to live with, their diagnosis? Each of these factors demonstrated value for patients and the organization. The challenge lies in clearly articulating this impact to senior leadership in ways that resonate and ensure lasting buy-in. How can you articulate the value of advocacy to your senior leadership team?

- Demonstrate different ways to measure the value of patient advocacy
- Examine how to work with cross-functional teams to ensure advocacy is prominent in every team

Amy Grover, Executive Director of Patient Advocacy, **CATALYST PHARMACEUTICALS**

9:45 AM	**Co-Presentation: Building Multi-Stakeholder Coalitions to Advance Molecular Profiling in Rare GI Cancers**

A successful industry–advocacy partnership is driving progress to improve outcomes for patients with rare gastrointestinal cancers. How has Partner Therapeutics, PanCAN, and the Cholangiocarcinoma Foundation collaborated to ensure that patients get the right tests to receive the right treatments? This session will highlight the development of a collaborative consensus manuscript on tumor molecular profiling and its role in identifying actionable targets in pancreatic and biliary tract cancers (PDAC and cholangiocarcinoma), offering practical insights into coalition-building, consensus development, and advancing access to precision medicine in rare cancers.

Anna Berkenblit, Chief Scientific & Medical Officer, **PANCREATIC CANCER ACTION NETWORK**
Matt Nestor, Vice President, Development Strategy and Partnerships, **PARTNER THERAPEUTICS**

10:30 AM	**Networking Break**
11:00 AM	**Debate Patient Compensation to Ensure Fair and Compliant Practices**

When conducting clinical trials, it is widely agreed that some form of compensation to patients is appropriate. However, things become trickier when dealing with trials that require more time and resources from the patient. Lazarex Cancer Foundation stated, "Travel costs remain one of the top barriers to cancer clinical trials, leaving a staggering 93% of cancer patients without the help they need to participate." While compensation can increase participation and address potential financial burdens, it also raises questions about incentivization and the potential for biased enrollment.

- Go over the complexities tied to compensation for patients
- Determine what is an appropriate and fair compensation

Susan Stein, US Patient Advocacy Lead, **ZAMBON GROUP**

11:45 AM	**Presentation by Axcela.bio**
12:30 PM	**Networking Lunch**
1:45 PM	**Transform Rare Disease Care through Applied Technologies, Data, and Media**

Rare disease patients face unique challenges in understanding their health and accessing effective treatments. Emerging applied technologies—such as wearables and AI-driven data analysis - are reshaping how patients track symptoms, understand why they don't feel well, and improve quality of life in real time. At the same time, media platforms play a powerful role in uniting communities, driving education, and influencing policy. How can technology and media accelerate scientific outcomes, foster patient empowerment, and create new opportunities for innovation in rare disease care.

- Explore how applied technologies can deliver real-time insights into patient well-being and advance scientific outcomes.
- Understand the psychological and quality-of-life benefits of empowering patients with knowledge about their condition.
- Examine how media can bring rare disease communities together, strengthen education, and influence policy to support better patient outcomes.

Thomas Bartlett, National Patient Ambassador, Research and MG Registry, **MGFA**

2:30 PM	**Case Study: Co-Create Meaningful Trial Awareness and Participation Support Materials**

This session explores how one company collaborated with a global network of patient advocates and families to co-create a robust suite of awareness and participation materials for their clinical trials. Because the studies span multiple age groups, the development process required careful tailoring to ensure materials would be age-appropriate, accessible, and meaningful for children, adolescents, and care partners alike.

- Gain insight into the perceived pain points and gaps with current recruitment and participation support materials
- Discover practical strategies for creating resources that support informed decisionmaking and strengthen patient and family engagement in clinical research

Sarah Friedhoff, Head of Patient Advocacy, **ENTRADA THERAPEUTICS**
Shannon Callison, Senior Clinical Trial Manager, **ENTRADA THERAPEUTICS**

3:15 PM	**Networking Break**
3:45 PM	**PANEL: Crossroads of Advocacy: Legacy, Influence, and the Future of Patient Voice**

Patient advocacy has always been a driving force for change—but the way advocacy shows up is evolving. For decades, nonprofit patient advocacy organizations have led with credibility, stewardship, and deep-rooted connection to patient communities. Today, they are joined by a rising wave of individual patient leaders, influencers, and digital storytellers whose reach and immediacy are reshaping the public conversation. These new voices are not replacing the old— they're adding dimension, urgency, and complexity to what it means to advocate.

- Explore how advocacy is evolving—and why this shift matters to patients, caregivers, and the system
- Go over the enduring role of nonprofit organizations in legitimacy, collective action, and policy advancement
- Discover the rising influence of individual advocates in accelerating awareness, storytelling, and community activation
- Understand legal, compliance, and funding considerations:
- Look to the hybrid future: What does collaboration look like between traditional and emerging advocacy voices?

Fatima Scipione, Vice President, Global Patient Affairs, **BLUEPRINT MEDICINES**
Teonna Woolford, CEO, **SICKLE CELL REPRODUCTIVE HEALTH EDUCATION DRIVE**
Anita Longoria, Patient Advocate, **MYASTHENIA GRAVIS SUPPORT GROUP**

4:30 PM	**PANEL: Partner with Patient Advocacy Groups: Strategies for Compliance and Impact**

Collaborating with patient advocacy groups is key to understanding patient needs and shaping better clinical and product outcomes. But how can organizations engage PAGs effectively while remaining compliant, from product development through clinical trials? How can you buildstrong, ethical partnerships that amplify the patient voice?

- List the benefits of collaborating with patient advocacy groups across the product lifecycle
- Acquire strategies for compliant engagement with PAGs during both development and clinical trials
- Go over practical approaches to integrate patient insights into organizational decisionmaking and trial design

Catherine Jackson, Senior Director, Patient Engagement and Advocacy, **MALLINCKRODT PHARMACEUTICALS**
Roya Hakimzadeh, Director, Patient Advocacy, **BLOOM SCIENCE**
Molly Keane, Senior Manager Patient Advocacy, **AMGEN**
Matt Nestor, Vice President, Development Strategy and Partnerships, **PARTNER THERAPEUTICS**
Sandra Shpilberg, Co-founder & COO, **ADNEXI**

5:15 PM	**PANEL: Collaborate with Patients throughout the Clinical Trial Protocol Design**

Engaging patients early in the trial process is no longer just a best practice but an expectation. Based on a study by Rare Revolution, trials that integrate patient input into protocol design can significantly reduce protocol amendments—amendments affect over 60% of trials and cost up to $500,000. But how early is "too early," and what role should patients play in shaping protocol design? How can you form patient advisory committees and integrate patient perspectives into trial guidelines? Oftentimes, the FDA wants to see that patients are involved at every stage of a trial, what are the best ways to demonstrate that collaboration?

- Discuss how to show the FDA you are creating a drug that meets unmet needs
- Navigate how to include patients in clinical trials from the beginning stages
- Allow patients to look through the trial guidelines to determine if they are too burdensome

Frank Rivera, President, **STRONGER THAN SARCOIDOSIS**
Jin Lee, CEO, **IMIDEOLOGY**
Sydney Gardner, Senior Manager, Patient Advocacy, **DENALI THERAPEUTICS**
Naziah Lasi-Tejani, Global Patient Partnership Group Leader, Hematology/Oncology, **ROCHE**

6:00 PM	**Day 1 Concludes**

DAY TWO

Wednesday, January 28th, 2026

ALL TIMES ARE IN PST

8:00 AM	**Registration & Networking Breakfast**
8:45 AM	**Chairperson's Recap of Day One** Fatima Scipione, Vice President, Global Patient Affairs, **BLUEPRINT MEDICINES**
9:00 AM	**PANEL: Strengthen US and Global Interactions in Patient Advocacy**

While US teams often lead with patient advocacy and community engagement, global teams face different challenges in integrating patient perspectives across diverse portfolios and regulatory environments. Despite perceived differences, the core goals remain the same, ensuring that patient voices shape development and access worldwide. How can US and global teams better align and collaborate and what obstacles are in the way?

- Discover strategies for stronger alignment between US and global advocacy teams.
- Explore common challenges and practical solutions for integrating patient perspectives across regions.

Anne Bruns, Executive Director, Patient Engagement, Neurology, **PTC THERAPEUTICS**
Amy Akers Teets, Global Head Patient Strategy, Specialty Care, **SANOFI**
Vera Toth-Fejel, Sr. Director, Patient Advocacy, **GOSSAMER BIO**
Ryan Cliche, Executive Director, **BREAST360 FOUNDATION**

9:45 AM	**PANEL: Navigate Health Equity and Healthcare Access Amid New Policy Shifts**

The current political climate has made diversity, equity, and inclusion in clinical research a sensitive subject, with some organizations retreating from the language of equity altogether. Yet avoiding these conversations risks undermining patient trust and failing to meet the needs of underrepresented populations. A recent national poll from the PAN Foundation's Center for Patient Research finds that over the past 12 months, 1 in 4 adults with any chronic health condition have advocated for policy, legislation, and/or regulation to improve access to healthcare. How can companies and patients responsibly navigate political pressures in order to advocate for what they want?

- Know the risks of diminishing DEI efforts in clinical studies and the potential impact on patients
- Develop strategies to maintain patient trust and ensure inclusive, patient-centered research in challenging environments
- Strategize ways for patients to advocate for improved healthcare access

Alycia Shilton-Lloyd, PhD, Executive Director, Hematology-Oncology, Patient Innovation & Engagement, Value & Implementation, **MERCK**
Cara Hunt, Senior Patient Advocacy Operations Specialist, **CYTOKINETICS**
Sonali Chopra, Head, Patient Advocacy Relations, **GENENTECH**

10:30 AM	**Networking Break**
11:00 AM	**Uncover the Future of Patient-Centric Marketing**

The pharmaceutical industry is undergoing a shift from traditional HCP-focused marketing toward more patient-centric models. With patients becoming increasingly proactive and informed about their health, pharma companies must evolve their strategies to engage directly with them. How can means such as direct-to-patient strategies build a stronger marketing plan?

- Strategize how to integrate digital tools in the marketing design
- Explain the pros and cons associated with direct to patient marketing
- Recognize the emerging role of influencer partnerships and what to consider when using them to reach patients

Johannah Ruddy, Senior Director of Patient Advocacy, **ARDELYX**
Danielle Jordan, Director, Marketing, **ARDELYX**

11:45 AM	**Innovation Hubs**

- Debate patient involvement in Phase 3 clinical studies
- Weigh the pros and cons of decentralized trials regarding equity, cost, and convenience
- Engage ambassadors inside your company to support the advocacy agenda and ensure buy in
- Discuss the importance of Patient Communities in clinical research and drug development

Devra Densmore, CEO & Principal, **ELEVATE ADVOCACY**

12:30 PM	**Lunch**
1:45 PM	**Co-Presentation: Elevate the Patient Voice: Co-Authoring Publications with Patients at the Forefront**

Including patients as co-authors on manuscripts is a powerful way to validate the patient perspective and highlight their lived experience. A survey of medical journal editors published in the NIH revealed that 69.2% view the inclusion of patient partners as authors on manuscripts as appropriate. This can improve the design of clinical trials and optimize care by enhancing our understanding of their personal experience with the disease. How can the patients work with different teams such as legal and compliance? What are the challenges from an industry and patient perspective?

- Grasp the value of patient co-authorship in amplifying advocacy and strengthening scientific publications
- Learn how to navigate legal and compliance considerations
- Build new strategies for cross-functional collaboration to embed patient voices into research

Steven Unger, Senior Director, Patient Experience, **BRISTOL MYERS SQUIBB**
Tiffany Valentine, Associate Director Patient Engagement, Global Purpose & Patient Experience, Corporate Affairs, **BRISTOL MYERS SQUIBB**

2:30 PM	**Understand the Ethics and Strategies for Sharing Individual Data During and Following Clinical Trial Participation**

Returning individual clinical trial results to research participants is evolving from an uncommon practice to a standard expectation that promotes ethical research and builds trust. Your team needs to understand the balance between the participant's right to information and the practical challenges of data return for all stakeholders.

- Discuss why patients want their individual trial results
- Discover best practices for determining which data can be shared and when, and practical tools to facilitate the process

Mindy Cameron, Patient Engagement Consultant, **ADVOCACY WORKS**

3:15 PM	**Engage with Cross-Functional Teams to Align Advocacy Strategies Company-Wide**

Advocacy thrives when it is embraced across the organization and not just within a single department. Yet legal, compliance, marketing, and communications teams can sometimes be hesitant to engage, creating barriers to patient-centered progress. A Lucid report found that 78% of employees believe that their company's leadership could do more to promote collaboration within their organization. How can you build trust, demonstrate value, and embed advocacy strategies to ensure alignment in your company?

- Understand the value of working with cross-functional teams
- Find ways to show value and how to utilize advocacy
- Strategize how to engage teams that may be reluctant to collaborate.

Jasmine Patel, Director, Patient Advocacy, **EDGEWISE THERAPEUTICS**

4:00 PM	**AI in Patient Advocacy: Opportunities, Challenges, and Practical Applications**

Artificial intelligence is increasingly shaping how patients are engaged and supported throughout clinical trials. It can be used to enhance efficiency and even as a component for diagnosis especially in rare disease. The NIH published a study that showed, "based on randomized clinical trials, AI-based tools improved medication adherence ranging from 6.7% to 32.7% compared to any intervention controls and current practices." How can AI enhance patient experiences and improve trial outcomes?

- Go over the role of AI in disease diagnosis and patient engagement
- Explore current applications of AI in clinical trials
- Discuss common challenges and pitfalls associated with integrating AI into patient advocacy efforts

J.P Sacksteder, Senior Director, Advocacy Relations, **GENENTECH**

Conference Concludes

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