

4th Annual

Chief Patient Officer Summit

July 15-16, 2024 | Hilton Boston Back Bay | Boston, MA



Conference Chair | Tricia Mullins,
Executive Director, Beigene



Kay Matthews, Executive Director,
Shades of Blue Project



Beth Frates, MD, Lifestyle Medicine
Clinician, Speaker and Author



Rene Russo, PharmD,
President, CEO, Xilio Therapeutics



Hear About the 2024 Event That Connects Executives Who Matter to the Future



The **4th Chief Patient Officer Summit** is the industry's largest, most detailed, and most trusted forum for revolutionizing patient engagement strategy. Based on your feedback, this year's all-new agenda features a special emphasis on understanding patient community influence in regulatory decision-making. Another important conversation new to the agenda exemplifies how stakeholders collaborate to advocate for patient access. Our 2024 program has a greater focus on actual examples of health equity work and includes important keynotes.

By popular demand, multiple sessions showcase the success of patient advocacy partnerships with researchers, clinicians, patients and HEOR colleagues in the publication of posters, papers, abstracts and more. Plus, a new session devoted to patient involvement in clinical trials includes panelists new to the program this year. Two concurrent workshops, included in the conference registration, will help you reach new heights in your profession.

These are just a very few of the new highlights you'll see on the agenda and experience in Boston, MA on July 15-16, 2024. DGE is delighted to present the 4th rendition of the Chief Patient Officer Summit and we look forward to seeing you there.

COMMENTARIES ON LAST YEAR'S EVENT

"HIGHLIGHT OF MY YEAR!

It was amazing to connect and learn from so many patient advocacy leaders. I learned so much from everyone in the room and was inspired by the patients and advocates who shared their stories. I am taking with me a lot, but most importantly a posture of listening and learning and commitment to true co-creation."

"INSPIRED!

2023 Chief Patient Officer Summit focused on raising the bar on patient innovation & engagement"

"The Chief Patient Officer Summit is consistently my favorite event for professionals in patient advocacy. **EXPERIENCED SPEAKERS, THOUGHTFUL AND RELEVANT CONTENT** and (most importantly) an opportunity to connect with like-minded industry advocates."

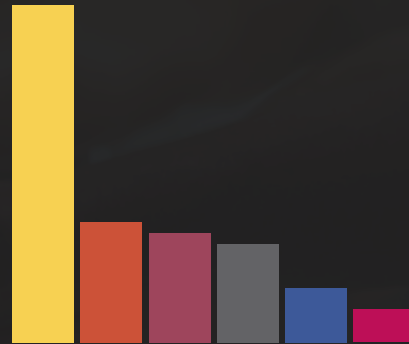


WHO ATTENDS

Chief Patient Officers, Heads, Vice Presidents, Directors and Specialists from pharmaceutical, biotechnology and medical device companies working in:

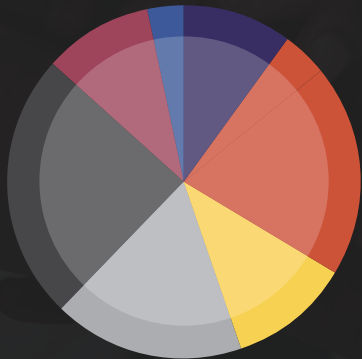
Attendance by Function

- Patient Advocacy59%
- Patient Engagement12%
- Patient Affairs10%
- Patient Education7%
- Marketing7%
- Patient Experience5%



ATTENDANCE BY TITLE

- C-Suite.....13%
- Exec Dir/Head15%
- Sr VP/VP20%
- Sr Dir.....18%
- Dir17%
- Assoc Dir.....10%
- Sr Mgr/Mgr7%



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Audra Boscoe
VP, Health
Economics,
Outcomes Research
& Data Science
Analytics
Agios
Pharmaceuticals



Abby Bronson
Vice President
Advocacy and
External Innovation
Edgewise
Therapeutics



Julia
Carpenter-Conlin
MSW, Head of
Patient Advocacy
Alkeus
Pharmaceuticals



Chelley Casey
Vice President,
Patient Advocacy
Wave Life Sciences



Sonali Chopra
Executive Director,
Patient Advocacy
Relations
Genentech



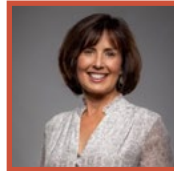
Gissou DeCotiis
Global Head of
Advocacy & Strategic
Relations, Global
Medical Affairs,
Oncology
Daiichi Sankyo



Ligia Del Bianco
Global Head, Patient
Advocacy, Corporate
Responsibility &
Community
Engagement
Biogen



Deepa Dahal, MBA
Co-Founder and
Executive Partner
DKI Health



Wendy Eler
Vice President,
Global Head, Patient
Experience, Patient
Advocacy & Patient
Caregiver Insights
AstraZeneca



Bethany Firem
Associate Director of
Global Patient Affairs
BioMarin



Amy K. Fisher
Head of Patient
Advocacy,
Spark Therapeutics



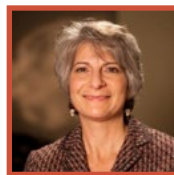
Kathleen Flynn
Chief Executive
Officer
**National Tay-
Sachs & Allied
Diseases Association**



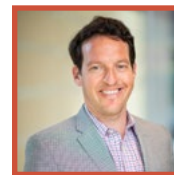
Beth Frates, MD
President, **American
College of Lifestyle
Medicine**; Director
of Lifestyle Medicine
& Wellness, **MGH**
**Department of
Surgery**; Faculty,
**Harvard University
Extension School**



Phil Gattone
CEO
**National Bleeding
Disorders
Foundation**
former CEO,
Epilepsy Foundation



Jayne Gershkowitz
Chief Patient
Advocate
Amicus Therapeutics



Lee Greenwood
Father and Advocate



David Gurzick, Ph.D.
Member
**Angelman
Biomarkers and
Outcomes Measure
Consortium (A-BOM)**



Jennifer Helfer
Senior Director,
Patient Advocacy
and Engagement,
Corporate Affairs
Viridian Therapeutics



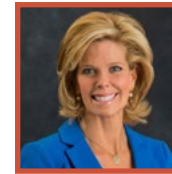
Holly John
Senior Director of Patient
Advocacy
Agios



Meg Kilcoyne
**Massachusetts State
Representative 12th
Worcester District**



Lisa Lacasse
President
**American Cancer Society
Cancer Action Network
(ACS CAN)**



Sharon Lambertson
Deputy Vice President,
State Policy and
External Outreach
PhRMA



Kay Matthews
Executive Director
Shades of Blue Project



Emily McGinnis
Chief Patient Officer &
External Affairs Officer
Taysha Gene Therapies



Kristen Mosdell
Vice President, Head of
Scientific Communications
Beigene



Tricia Mullins
Executive Director, Global
Head, Early Patient
Engagement & Professional
Societies
Beigene



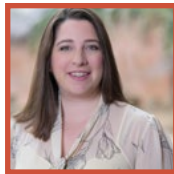
Ifeyinwa Osunkwo, MD
Senior Vice President,
Chief Patient Officer
Novo Nordisk Rare Disease



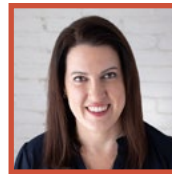
Luke Rosen
Founder, **KIFIA.ORG**,
Partner, **Every 1 Advocacy**,
Father/Advocate



Rene Russo, PharmD
President, Chief Executive
Officer
Xilio Therapeutics



Lisa Savitt
Vice President
SmithSolve



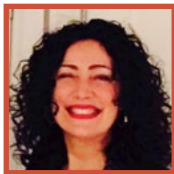
Regan Sherman
Head of Patient Advocacy
Entrada Therapeutics



Kate Tighe
Vice President, US Public
Affairs and Patient
Advocacy, Immunology
Sanofi



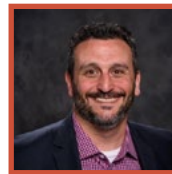
James Valentine
Director, Hyman
Phelps & McNamara



Mary Wachter
Executive Director,
State and Local
Government Affairs
Genentech



Christopher Chauncey
Watson, PhD, MHS,
Global Marketing Director,
HIV Franchise, **Gilead
Sciences**; Researcher in
Residence, **Morgan State
University Center of Urban
Health Equity**



Michael Zincon
Senior Director, Patient
Advocacy
Pfizer



DAY ONE

Monday, July 15, 2024

7:00 *Registration and Networking Breakfast*

8:00 *Chair's Welcome and Opening Remarks*

Tricia Mullins, Executive Director, Global Head, Early Patient Engagement & Professional Societies (Ex-China), BEIGENE

8:15 **TRAIL BLAZER KEYNOTE**
Knowledge Builds Community Trust

Kay Matthews, Executive Director, SHADES OF BLUE PROJECT

Kay Matthews founded the Shades of Blue Project in 2016 shortly after the stillborn death of her daughter Troya Simone. As she built the Shades of Blue Project, she understood that she was not alone in her experience: maternal morbidity rates of Black women were only worsening, and Black maternal mental health support systems were nonexistent, poorly managed, or resulted in Black mothers having their children removed from their homes. This lack of Black maternal mental health care and continued ill treatment of Black birthing individuals spurred Matthews to create the I.N.S.P.I.R.E. Method Training. A unique training based on compassion, I.N.S.P.I.R.E. is specific to women of color can be implemented by doulas, midwives, clinicians, and those facilitating support groups. Kay founded Black Maternal Mental Health Week in 2018 and is a fierce advocate of Black birthing individuals across the world.

9:00 **Presentation by Parexel**

9:45 **PANEL | Decode the Regulatory Pathway and Community Influence in Regulatory Decision-Making**

Patient communities can have enormous influence in regulatory review of new drugs. By sharing their perspective on disease burden, how disease progression is measured and the risk-benefit ratio of potential new therapies, patients and their loved ones provide invaluable insight to regulatory decision-makers. Patient advocacy leaders can ensure the patient voice is shared effectively with regulators by working earlier and more closely with regulatory colleagues. Benefit from hearing directly from those who have experience aligning patient engagement with regulatory strategy.

- Understand the regulatory timeline and how and when to demonstrate how conditions impact daily life and top priorities for treatment goals
- Identify the appropriate channels and preparation needed to effectively share patient/caregiver experiences
- Educate patient communities about opportunities to provide input (e.g., advisory committees, patient-focused drug development meetings)

PANELISTS:

Kathleen Flynn, Chief Executive Officer, NATIONAL TAY-SACHS & ALLIED DISEASES ASSOCIATION

Lee Greenwood, FATHER AND ADVOCATE

James Valentine, Director, HYMAN, PHELPS & MCNAMARA

MODERATOR:

Regan Sherman, Head of Patient Advocacy, ENTRADA THERAPEUTICS

10:30 *Networking Refreshment Break*

11:00 **PANEL | Shape Policy for Patient Benefit: Exploring Collaboration in Biomarker Testing Advocacy**

In this informative session, we will explore biomarker testing policy and how various stakeholders across industry, patient advocacy groups and the government collaborate to advocate for patient access.

- Discuss the challenges and opportunities involved in shaping policies that ensure equitable access to biomarker testing for patients
- Delve into the strategies employed by Genentech State and Local Government Affairs, ACS CAN, and the Massachusetts state government
- Foster collaboration and advocate for policies that prioritize patient needs

PANELISTS:

Mary Wachter, Executive Director, State and Local Government Affairs, GENENTECH

Lisa Lacasse, President, AMERICAN CANCER SOCIETY CANCER ACTION NETWORK (ACS CAN)

Meg Kilcoyne, MASSACHUSETTS STATE REPRESENTATIVE 12th Worcester District

11:45 **Amplify Patient Voice in Market Access**

Every year, payers make it harder for patients to access their doctor-prescribed treatments, burdening healthcare providers, negatively impacting clinical outcomes, and impairing patient quality of life. But recent years have seen patients' influence on access decision-making grow. Have we reached a tipping point? And how can drug developers support patients' efforts to win equitable access to beneficial therapies? This session examines recent trends related to access to medicines, and the influence patients can have on these decisions.

- Utilization management: the tactics and technologies insurers and PBMs in the US and HTA agencies in Europe are using in 2024 to limit access and their effects on patients
- Patient voices rising: lessons learned from 3-5 recent case studies where patients and advocates favorably impacted drug access
- How pharma can engage with patients, advocates, policymakers, and other stakeholders in communicating the totality of a particular medicine's value

Deepa Dahal, Co-Founder and Executive Partner, DKI HEALTH

Phil Gattone, CEO, NATIONAL BLEEDING DISORDERS FOUNDATION;

former CEO, EPILEPSY FOUNDATION

12:30 *Networking Luncheon*

1:45 **Elevate Equity from Inception and Sustain Inclusion through Post Marketing**

This session starts with an interactive exercise to help you understand your own bias through eliciting ideas about power and privilege. Through a case study approach, you will be guided toward elevating equity as a strategic imperative throughout the product lifecycle.

- Uncover equitable solutions for including patient voices
- Understand the impact of social determinants of health and disability inclusion on clinical trial design
- Define sustainability measures to achieve critical success factors

Christopher Chauncey Watson, PhD, MHS, Global Marketing Director, HIV Franchise, GILEAD SCIENCES;

Researcher in Residence, MORGAN STATE UNIVERSITY CENTER OF URBAN HEALTH EQUITY

2:30 **Operationalize Patient Inclusivity: Anticipate, Minimize, and Exit the “Sticky Middle”**
One strategic function of patient advocacy departments is to define and operationalize patient inclusivity across an organization. This includes building consensus, developing infrastructure, and educating or implementing cross-functionally. Given evolving priorities, resources, and external pressures, advocacy professionals may find themselves in the “sticky middle” – that place where patient inclusivity initiatives are deprioritized and timelines lag

- Assess organizational readiness and manage expectations
- Secure cross-functional buy-in from key stakeholders
- Navigate changing priorities and resistance; overcome obstacles
- Equip and empower all functions to adopt a patient-inclusive culture
- Maintain momentum and measure impact

Lisa Savitt, Vice President, SMITHSOLVE
Amy K. Fisher, Head of Patient Advocacy, SPARK THERAPEUTICS, INC.

3:15 *Networking Refreshment Break*

3:45 **Drive Community Health Equity by Uniting National and Local Collaborations**
This session explores collaboration with leading national patient advocacy organizations, ACS, NMSS, and ADA on local health equity work in collaboration with community based organizations.

- Understand work with the ADA in Birmingham, highlighting collaborative efforts to address patient access issues from screening to specialty care.
- Explore the initiatives undertaken with NMSS to tackle neurology desert areas, ensuring access to quality care and support for individuals affected by Multiple Sclerosis.
- Learn about the collaborative work with ACS to advance cancer health equity, aiming to reduce disparities in cancer prevention, treatment, policy and support services.

Sondli Chopra, Executive Director, Patient Advocacy Relations, GENENTECH

4:30 **PANEL | Examine Publishing Trends with Partners**
Advocacy executives are teaming with partners including researchers, clinicians, HEOR and patients/caregivers. Learn more about successful case studies for partnering to publish posters, papers, abstracts, reports and more.

- Publish about patient-focused initiatives at scientific congresses and in scientific journals
- Incorporate patient authors into clinical publications
- Share focus group data back to participants, researchers and clinicians
- Increase patient and caregiver access to clinical study data through Publication Plain Language Summaries

PANELISTS:
Emily McGinnis, Chief Patient Officer & External Affairs Officer, TAYSHA GENE THERAPIES
Wendy Erler, Vice President, Global Head, Patient Experience, Patient Advocacy & Patient Caregiver Insights, ASTRAZENECA
Kristen Mosdell, Vice President, Head of Scientific Communications, BEIGENE

5:15 **Patient Assistance: What You Should Know As A Patient Advocate**
Sharon Lamberton, Deputy Vice President, State Policy and External Outreach, PHRMA

5:45 *Networking Reception*

6:45 *Close of Day One*

DAY TWO

Tuesday, July 16, 2024

7:30 *Registration and Networking Breakfast*

8:30 *Chair’s Welcome and Opening Remarks*
Tricia Mullins, Executive Director, Global Head, Early Patient & Engagement & Professional Societies, BEIGENE

8:45 **RESTORE - RECHARGE - RENEW KEYNOTE**
PAVING the Path to Wellness: Thriving with a Healthy Body, Peaceful Mind and Joyful Heart
Beth Frates, MD, President, AMERICAN COLLEGE OF LIFESTYLE MEDICINE; Director of Lifestyle Medicine & Wellness, MGH DEPARTMENT OF SURGERY; Faculty, HARVARD UNIVERSITY EXTENSION SCHOOL
Elizabeth (Beth) Pegg Frates, MD is a pioneer in Lifestyle Medicine education, an award-winning teacher at Harvard, and currently works with patients to help them adopt and sustain healthy habits. Dr. Frates is the Director of Lifestyle Medicine & Wellness at the MGH Department of Surgery, President of the American College of Lifestyle Medicine and an accomplished author. Since 1996, Dr. Frates has been on faculty at Harvard Medical School and has won multiple teaching awards for her work. Dr. Frates developed the concept of a Lifestyle Medicine Interest Group (LMIG) for medical schools that do not currently offer a course on Lifestyle Medicine and has been successfully running an LMIG at Harvard Medical School (HMS) since that time.

9:30 **Gain Techniques for Successful Measurement and Reporting**
It’s imperative for you to know what differentiates your advocacy work. Understand more about ways to establish an effective metrics framework that enables you to communicate the value of your advocacy program organization-wide.

- Be proactive and own the narrative on what you measure and why
- Know what “good” looks like and the steps you need to take to get there
- Tips for building a deck to communicate priorities and accomplishments in language that will be well received

Kate Tighe, Vice President, US Public Affairs and Patient Advocacy, Immunology, SANOFI

10:15 *Networking Refreshment Break*

10:45 **PANEL – Achieve Global Leadership in Patient Advocacy and Engagement**
Leaders in global patient advocacy and engagement thrive in ever-changing, dynamic environments with both external and internal collaborators. Gain insight from case examples and success stories on global advocacy.

- How to build your team of internal champions around the world
- Collaborate with local and regional stakeholders

- Engage on various advocacy boards globally
- Examine regulatory perspective and including patients in all process steps (HTA, FDA ODAC)

Panelists:

Gissoo DeCotiis, Global Head of Advocacy & Strategic Relations, Global Medical Affairs, Oncology, DAIICHI SANKYO

Ligia Del Bianco, Global Head, Patient Advocacy, Corporate Responsibility & Community Engagement, BIOGEN

11:30 **PANEL - Involve Patients and Caregivers in Clinical Trials**

This session delves into the heart of patient-centric clinical research, exploring innovative frameworks that integrate patient insights into the fabric of clinical trials. We'll uncover the unique challenges and opportunities in cell and gene therapy trials from a patient perspective, and share strategies to design trials that not only listen to but also act on patient input.

- Examine patient needs in cell and gene therapy trials
- Design trial protocols that reflect patient input

PANELISTS:

Abby Bronson, Vice President Advocacy and External Innovation, EDGEWISE THERAPEUTICS

Bethany Firem, Associate Director of Global Patient Affairs, BIOMARIN

Luke Rosen, Founder, KIF1A.ORG, Partner, EVERY 1 ADVOCACY, Father/Advocate

David Gurzick, Ph.D., Member, ANGELMAN BIOMARKERS AND OUTCOMES MEASURE CONSORTIUM (A-BOM)

Chelley Casey, Vice President, Patient Advocacy, WAVE LIFE SCIENCES

12:15 **Networking Luncheon**

Luncheon Table Topics

Optimize peer-to-peer learning by crowdsourcing solutions to common challenges. The connections you make will become a valuable takeaway.

- 1) Patient advocacy in small companies
- 2) Plain language summaries
- 3) Patient advocacy/commercial team collaboration
- 4) Patient advisory boards and leadership councils
- 5) Patient advocacy/compliance team collaboration

1:15 **LEADERSHIP KEYNOTE**

Rene Russo, Pharm.D., President and Chief Executive Officer, XILIO THERAPEUTICS

Dr. Russo is an accomplished biotechnology CEO with over 20 years of experience leading R&D and commercialization in the biopharmaceutical industry across a range of therapeutic areas, including oncology. As an executive leader, Dr. Russo has led successful teams from early preclinical research through all phases of clinical development, registration, and commercialization to bring innovative therapies to patients across the United States and Europe. She is currently the CEO of Xilio Therapeutics (NASDAQ: XLO), a clinical-stage company focused on developing tumor-selective, potent immuno-oncology therapeutics. Before Xilio, Dr. Russo was the President and CEO of Arsanis (NASDAQ: ASNS), a company developing monoclonal antibodies to prevent and treat serious infectious diseases. Prior to Arsanis, Dr. Russo spent 12 years at Cubist Pharmaceuticals (NASDAQ: CBST), a leading global anti-infective company that Merck acquired for \$9.6B.

1:45

CASE STUDY – Red Cell Revolution Reveals Authentic Patient Engagement

Through an evidence-based advocacy approach, a company's patient advocacy function can help generate the data needed to support clinical development planning, regulatory submissions, commercialization, and market access efforts. Through the Red Cell Revolution, an example of cross-functional collaboration, our patient advocacy and HEOR leaders are teaming up to drive greater value for patients.

- Breaking down silos, both internal and external
- Working with patients, caregivers, and physicians to co-create solutions
- Creative approaches to data generation and communication
- Using data to support dialogue and relationship building

Holly John, Senior Director of Patient Advocacy, AGIOS

Audra Boscoe, VP, Health Economics, Outcomes Research & Data Science Analytics, AGIOS

2:30 **Networking Refreshment Break**

3:00 **Choose From Two Concurrent, 90 minute workshops**

WORKSHOP #1:

Develop Advocacy Strategy and Cross-Functional Partnerships

This workshop helps you transition from managing critical initiatives to innovative development and planning of advocacy strategy. Its main focus is on building strategic engagement plans that align with the mission of the business and on valuable communication techniques and ideas for building cross-functional workstreams and partnerships. Learn from innovative methods for co-creating with patient communities. Excellent opportunity to better understand potential expectations for short and long term career advancement.

Workshop Leaders:

Julia Carpenter-Conlin, MSW, Head of Patient Advocacy, ALKEUS PHARMACEUTICALS, INC.

Jennifer Helfer, Senior Director, Patient Advocacy and Engagement, Corporate Affairs, VIRIDIAN THERAPEUTICS

add Michael Zincone, Senior Director, Patient Advocacy, PFIZER

WORKSHOP #2:

Executive Leadership Summit

This workshop helps you to chart next steps on the path to Chief Patient Officer and beyond. Key takeaways include critical experiences and approaches for working with the board of directors and C-Suite, broadening financial acumen beyond advocacy and achieving consensus. Discuss the obstacles and opportunities involved in cultivating teams, engaging with patient advocacy organizations on thought leadership and stewarding your brand. Brainstorm disruptive and effective solutions for differentiating your program and power. Participants must be a Chief Patient Officer, Vice President or Executive Head with 8+ years of experience.

Workshop Leaders:

Jayne Gershkowitz, Chief Patient Advocate, AMICUS THERAPEUTICS

Wendy Erler, Vice President, Global Head, Patient Experience, Patient Advocacy & Patient Caregiver Insights, ASTRAZENECA

Ifeyinwa Osunkwo, MD, Senior Vice President, Chief Patient Officer, NOVO NORDISK RARE DISEASE

4:30

Conference Concludes

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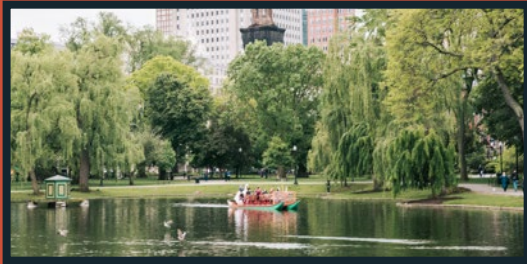
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Our special attendee room rate will be available until June 26, 2024.

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ARE YOU READY TO REGISTER?

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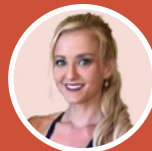
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