Genetic Alliance
Celebrates
30 Years
March 9 & 10, 2017
Bethesda North Marriott Hotel & Conference Center
Our Mission

Genetic Alliance engages individuals, families, and communities to transform health.

Individuals and families need and deserve opportunities to be active participants in health, from services in traditional health settings to groundbreaking research endeavors.

Genetic Alliance is resolute that people come first. We partner with individuals and communities to transform health systems to respond to what people most need.

We convene powerful networks, deliver actionable information, build intuitive tools, and drive policy decisions.

Core Values

Genetic Alliance commits to accomplish our mission with integrity, and to live by these values in everything we do.

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<thead>
<tr>
<th>Collectivity:</th>
<th>We believe that everyone values health and well-being for themselves and those they love.</th>
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<tr>
<td>Openness:</td>
<td>To achieve better health for all, we must embrace the diverse priorities of our allies while contributing to a common goal</td>
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<td>Transparency:</td>
<td>We must actively understand and honestly communicate our biases and ambitions,</td>
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<td>Trustworthiness:</td>
<td>Practicing our mission, in order to cultivate and sustain trust.</td>
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<td>Vulnerability:</td>
<td>And yet, we must also risk our comfort and be willing to trust in others,</td>
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<td>Intersectionality:</td>
<td>For the factors that influence health and happiness are myriad and too great for any one organization to solve.</td>
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<td>Commitment to Agency:</td>
<td>Indeed, we must support the inherent power of people’s choices and build systems that meet their needs,</td>
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<tr>
<td>Inclusivity:</td>
<td>To ensure that these benefits are available to all people.</td>
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<td>Responsibility:</td>
<td>We are responsible for the health of ourselves and all others, and,</td>
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<tr>
<td>Tempered Urgency:</td>
<td>We must act with purpose and haste to create the change we seek within our lifetimes.</td>
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Dear Genetic Alliance family,

So much has happened in these past 30 years to enhance the lives of everyone affected by genetic disease. In thinking back to our beginnings as the Alliance of Genetic Support Groups in 1986, little did we know that our original mission to create a coalition of voluntary genetic organizations and healthcare professionals would become the tremendous force Genetic Alliance is today.

Initially, we hoped that the coalition would link genetic advocacy groups to the scientific and research communities—and it has. We envisioned that public education about genetic conditions would increase—and it has. We conceived the idea of a true partnership between our citizens who have a genetic condition and their health providers—that has happened.

We founding members of the Alliance planted the seeds, but you who have supported Genetic Alliance through the years are the ones who grew these seeds into the flourishing international organization it is today. Personally, I feel extremely gratified that a leader like Sharon Terry believes in the importance of our original mission to form a true partnership among families and the medical and scientific communities, and to continue to work to improve the availability and appropriateness of genetic services.

Congratulations to Sharon and to all of you who have contributed to the success of Genetic Alliance for the past 30 years!

Sincerely,

Joan O. Weiss
Joan O. Weiss is the founder of Genetic Alliance, formerly known as the Alliance of Genetic Support Groups. A clinical social worker by training, she responded to a request by Dr. Victor McKusick at Johns Hopkins to provide support to genetic patients and their families and voluntary genetic organizations, well before the sequencing of the human genome.

In 1986, Joan founded the Alliance of Genetic Support Groups. She also became the co-director of the Human Genome Education Model (HuGEM) and published articles in numerous books and journals.

Joan retired as director of the Alliance in 1996. During her 10 years of leadership, the organization grew from a hotline to a staffed venture promoting policy change, improved research, and broader public education on the challenges and promises of genetics.

Joan continues her interest in the field, recently hosting a genetics/genomic panel discussion for Somerset House, where she resides. She is honored to be a Pioneer of the National Association of Social Workers and a member of the Cosmos Club. Her latest passion is as an artist.

However, her family always comes first—husband Stan, a retired lawyer and bio ethicist; son Michael, a neurologist at the University of Washington; and daughter Betsy, who teaches film making and the history of film at Tulane University. Jonathan, who helped Joan with the beginnings of the Genetic Alliance, died as a young adult after a heart transplant. Joan and Stan also enjoy their three wonderful grandchildren and taking classes on a variety of subjects at American University.
Dear Genetic Alliance families, staff, and friends!

From 1996 to 2003, I had the unique opportunity and pleasure to serve as the Genetic Alliance’s second Executive Director. Over my short 7 years, we built on the pioneering work of Joan Weiss and set the stage for Sharon Terry, current and indefatigable CEO, who further expanded the Genetic Alliance’s role as a compassionate voice and advocate for children, adults, and families living with genetic conditions.

Those years, as the map of the human genome was first completed, opened my eyes to the new and evolving—almost exploding—world of genetics. We were just beginning to envision how this new, powerful science, guided and empowered by thoughtful and informed consumer advocates, could potentially deliver life-changing health options to families, adults, and children experiencing the challenging health effects of their own genetic heritage.

We worked together to change our name from the Alliance of Genetic Support Groups to the Genetic Alliance—a change reflecting our transition from focusing solely on patient organizations into a broad-based partnership with the other stakeholders working within the continuum of research to services. Together with researchers, clinicians, and ethicists, we worked with our vast membership of patient organizations to take on important issues in the genetics community.

In the growing discussions about genetic discrimination, Genetic Alliance represented the voice, experience, hopes of families living with genetic conditions. Finally, in 2008, the Genetic Information Nondiscrimination Act was passed. Even after all these years, I can still recall the boundless energy, passion, creativity, and commitment that we all brought to the task of making the Genetic Alliance an indispensable resource and essential voice in all discussions around genetics research and healthcare.

Now 14 years later, I have the unique pleasure to stand side-by-side with Joan and Sharon in celebration of Genetic Alliance’s 30th anniversary. We stand together in testament to how far Genetic Alliance has come and how we have grown over the years of our combined leadership.

Where will the next 10 years take us?

Greetings to everyone in the Genetic Alliance community and family!

Mary E. Davidson
I’d like to think that my small efforts over many years in some small way helped to move the arc of social justice and equality—ever so slowly and painstakingly—and to improve access to the best that healthcare has to offer ALL of us.

My involvement was a step-by-step process advancing through a range of diverse activities over more than 50 years as a student, volunteer, social worker, and leader of social action, advocacy, and nonprofit organizations. I volunteered as a high school and college student. My professional training was as a clinical social worker after 2 years as a Peace Corps community organizer in the urban and rural communities of northwestern Brazil. For more than 30 years, I was a member of a community clinical/psychiatric practice. I also spent more than 20 years working with and spearheading various projects and organizations.

I was always looking for ways to better the lives of a broad range of people involved in diverse issues, including sight and hearing challenged children, German juvenile delinquents, civil rights, poor Brazilian mothers and children in need of healthcare and community services, Bowery alcoholic and homeless men, international adoption in Japan, cross-cultural marital issues, pregnant and abandoned teenagers, people with chronic pain and serious medical conditions, Vietnamese mothers and their half-American children, individuals and families with a range of psychiatric and social challenges, children with learning and school challenges, underage refugee resettlement, and many others. It was this long history of involvement, along with the experience of genetic challenges in my own family, that made for a perfect match with the Genetic Alliance in 1996.

I am now a proud grandmother of four young and active grandsons (who, fortunately, live in DC), between the ages of 4 and 7—Jacob, Zev, Rhys, and Hugo. I continue to support causes related to universal quality healthcare and broadening opportunities for all people.
Dear Friends,

These 2 days we take a breath together to slow down and ponder this: 30 years of glorious work in advocacy, policy, technology, and education! Quite amazing.

I stand on the shoulders of giants. Read the wonderful letters from Joan Weiss, our founder, and Mary Davidson, former Executive Director. They are great mentors to me. They set a solid foundation for this organization in a world where genetics and genomics were just emerging (check out our timeline for a bit of perspective on this journey).

I met Genetic Alliance—and Joan and Mary—at the 10th anniversary celebration, when Francis Collins sang “Joan O. Weiss” to the tune of Edelweiss! It is significant to me that the three of us have been at each of the major anniversary celebrations of Genetic Alliance together.

Yes, bravo to Genetic Alliance and all our partners and supporters! And we don’t rest on our laurels. At every one of these big anniversaries Genetic Alliance asks big questions. Does the world still need us? Are we meeting that need as well as possible? What boundaries need to be pushed? How can we be most effective, most compassionate, most disruptive? To what are we called as the world of health, healthcare, genetics, biomedical research, and bioethics evolve? How are we showing up in the world? We will be engaging with you in these and other questions here.

These 2 days we are “investing our comfort,” moving beyond what is familiar, to experiment with how we can alleviate suffering, support health, and further well-being. These 2 days we are uniting as a community of diverse stakeholders, all with our eyes on the same North Star, call it what we will—better health, better life, wellbeing. Let’s do this with an urgency that is very real, for those who cannot take the steps we can—sometimes quite literally.

The best time was 20 years ago, the second best time is now. Let nothing else be “second best”; let’s go into this together. Let’s look for a YES in all we do. Let us take gentle care of one another while we go.

In great love for all of our community and communities,

Sharon
Sharon F. Terry is President and CEO of Genetic Alliance, a civic enterprise engaging individuals, families, and communities to transform health. Genetic Alliance works to provide programs, products, and tools for ordinary people to take charge of their health and to further research.

As “just a mom” with a master’s degree in Theology, Sharon cofounded PXE International a research advocacy organization for the genetic condition pseudoxanthoma elasticum (PXE) in response to the diagnosis of PXE in her two children in 1994. With her husband, she co-discovered the ABCC6 gene and patented it to ensure ethical stewardship in 2000. Subsequently, she developed a diagnostic test and conducts clinical trials. Sharon is the author of 150 peer-reviewed papers, of which 30 are clinical PXE studies.

She serves in a leadership role on many major international and national organizations, including the Precision Medicine Initiative Cohort Advisory Panel. She is on the editorial boards of several journals. She led the coalition that was instrumental in the passage of the Genetic Information Nondiscrimination Act. She received an honorary doctorate from Iona College for her community engagement work in 2006; the Research!America Distinguished Organization Advocacy Award in 2009; and the Clinical Research Forum and Foundation’s Annual Award for Leadership in Public Advocacy in 2011. She is Co-PI of the PCORnet Coordinating Center, member of the Blue Ribbon Panel’s Working Group on Enhanced Data Sharing for the Cancer Moonshot, and Ashoka Fellow. With her husband Patrick, Sharon is an avid paragliding pilot, rock climber, and weekend farmer.
**Timeline**

**1986:** Joan Weiss and colleagues founded the **Alliance of Genetic Support Groups**
- Joan Weiss becomes first Executive Director
- First office opens in Chevy Chase, MD

**1987:** Joan Weiss conducts survey of genetic support groups
- **Healthcare Consumer Speakers Bureau** established
- March of Dimes offers initial grant to support the Alliance

**1988:**
- 1st edition of **Directory of Genetic Support Groups** published
- **Alliance Empowerment** conference

**1989:**
- **Genetic Information Hotline** established
- Office moved to current location in Washington, DC

**1990:**
- Joan Weiss secures HRSA funding for the Alliance (continues to the present day)
- **New England Peer Support** conference

**1991:**
- **Peer Support Guide** completed

**1992:**
- **Health Insurance Resource Guide** published
- **Intergrating Consumers into the Regional Genetics Networks** published

**1993:**
- **Healthcare in Flux: How will Families with Special Needs Fit in?** conference

**1994:**
- **Informed Consent: Participation in Genetic Research Studies** published

**1996:**
- Mary Davidson becomes Executive Director
- **Tenth Anniversary Gala**

**1997:**
- **Coalition for Genetic Fairness** is founded to work for Genetic Information Non-discrimination Act
- Mary Davidson at White House kickoff for legislation protecting the privacy of genetic information

**1998:**
- **Forging Genetic Partnerships: Research, Policymakers, and Consumers** conference
1999: Name changed to Genetic Alliance

2000: *Cultural Diversity in Genetics* conference
White House recognizes Genetic Alliance’s role in Human Genome Project

2001: *People’s Genome Celebration* at the Museum of Natural History

2002: *Directory of Genetic Support Groups* becomes digital
*Train the Trainer* conference

2003: *Genetic Alliance BioBank* is founded
*Genetic Alliance Institutional Review Board* is established
The Hotline becomes the *Genetics and Rare Disease Information Center (GARD)*

2004: *Joining Our Journeys: One Step at a Time* conference
Sharon Terry becomes CEO
*Wikiadvocacy.org* created

2005: *Institute for Advocacy* launched
*Leadership in Alliance: Leveraging Voices, Advancing a Vision* conference
Public campaign begins for NIH Open Access Policy

2006: *20th Anniversary Celebration* at the National Geographic Society
*Excellence in Advocacy* conference
*Genetics Day on the Hill*
*Genomics, Cancer Care and Advocacy* published
*Understanding Genetics: A Guide for Patients and Health Professionals* published

2007: *Eyes on the Prize: Truth Telling about Genetic Testing Summit* and monograph published
*Genetics Day on the Hill*
*Genetic Testing Stories* monograph published
*National Consumer Center for Genetics Resources and Services* established
*The Year of Advocate* conference
**Timeline, continued**

**2008:**  *Family Health History Tool* is released  
Genetics Day on the Hill  
Genetic Information Non-discrimination Act passed  
Making Sense of Your Genes: A Guide to Genetic Counseling published  
Transformational Leadership conference

**2009:**  Discovering Openness in Health Systems conference  
Genetics Day on the Hill  
GeneScreen: A Night of Film on Health and Genetics  
Newborn Screening Summit  
Trust It or Trash It: Creating & Assessing Health Information meeting and monograph

**2010:**  Advancing Novel Partnerships conference  
Community-Centered Family Health History. Collaboration Across Communities: How Do You Make Research Community-Specific and Universally Relevant? published  
Gene Screen: A Night of Film on Health and Genetics  
Genetics Day on the Hill  
Research!America award: Paul G. Rogers Distinguished Organization Advocacy Award  
Testimony before the House Committee on Oversight and Government Reform about Public Access to Federally Funded Research  
Testimony before the House Appropriations Committee about gene patenting  
Testimony before the House Committee on Science and Technology about standards  
Translational Research Enterprise—What Are We To Do? Meeting

**2011:**  25th Anniversary Celebration at the National Geographic Society  
25th Anniversary Year conference  
Baby’s First Test is launched  
Clinical Research Forum’s Public Advocacy Award  
Genetics Day on the Hill  
Future of Public Health Genomics meeting  
Platform for Engaging Everyone Responsibly (PEER) created
2012:  *Directory of Diseases* online becomes *DiseaseInfoSearch.org*
Genetic Testing and Data Management: Improving Health Outcomes, Disease Management, and Accountable Care Delivery Summit
PEER wins $350,000 to create crowdsourced cross-condition registry

2013:  *Advocacy ATLAS: Accessible Tools for Leadership and Advocacy Success* launched
Ashoka Changemakers First Prize for PEER
*Beyond the Bloodspot* summit
*GenesInLife.org* is launched
Forbes Best Business Model for Transforming Health Systems for PEER
Newborn Screening Saves Lives Act reauthorized
*Powerful Patient Data: Genomics and Family Health History in Health IT* summit
Testimony before the Senate HELP committee on newborn screening

2014:  *Community Engaged Network for All* launched
Multimillion-Dollar Newborn Screening Award
Robert Wood Johnson Foundation Pioneer Award for PEER

2015:  *Baby’s First Test* available in Spanish
Fielded a national needs assessment *Understanding Access to and Quality of Genetic Services*
Genetic Alliance becomes part of the *PCORnet Coordinating Center*
*Perinatal Nutrition Working Group* finds new home in Expecting Health
Platform for Engaging Everyone Responsibly (PEER) recognized in White House conference

2016:  *Building Trustworthiness in PCORnet* conference
Sharon Terry presents at TEDMED
*White House Precision Medicine Summit*

2017:  *Co-creating a Healthy Future: 30th Anniversary* conference
Genetic Alliance Council

Kemp Battle—Secretary
Catalytic Change Agent

Kelly Edwards, PhD
Associate Professor, University of Washington School of Medicine

Shantanu Gaur, MD—Treasurer
Co-founder, Allurion Technologies

Usama Malik, MBA
Founder and Managing Director, InnoAction Advisory Services

Sharon F. Terry, MA—President
PXE International, Inc.

(See Biographies page for photos and bios)

Genetic Alliance Staff

Joanna Ball
Digital Community Manager

Ruth Child
Chief Financial Officer

Andrea Goodman
Director of Engagement

Natasha Bonhomme
Vice President of Strategic Development

Lillian Duffield
Administrative Assistant

Yuliya Ilchyk
Executive Assistant

Jordan Capizola
Program Assistant

Jeffrey Giorgi
Communications & Operations Assistant

Alyson Krokosky
Assistant Director
Genetic Alliance is celebrating its 30th anniversary. Consistent with our desire to always focus on what matters, this meeting assesses four areas critical to a learning health system, focused on outcomes that matter to people. As we begin a new Administration, it is essential we create a shared vision. We consider tensions in health: from services to research to public health systems.

This is a highly interactive conference, with a blend of the best of grassroots organizing and unconference. We engage with the goal of concrete outcomes, laying the groundwork in each of the four areas and guiding us to work with each other to design projects to advance health. The outcomes will be tangible projects accomplished by formal and informal networks present at the meeting and beyond.

Areas of focus:
- Engagement: A national and/or local approach
- People-centered design in health
- High touch and/or high tech
- Radical innovation and/or iterative improvement
Agenda

Thursday, March 9, 2017

7:30 – 8:30 AM Registration and Breakfast Salon A-C

8:30 – 9:15 AM Welcome and Orientation to the Day Salon D
Sharon F. Terry, President and CEO, Genetic Alliance
Participant-centric Focus
Joe Selby, Executive Director, Patient-Centered Outcomes Research Institute

9:15 – 10:30 AM Opening Plenary Session Salon D
Considering tensions in health from services to research to public health, thought leaders lay the groundwork for us to work with each other to design projects that will advance health.

• Blinded by stereotypes: focusing on the individual
  Adolph Falcón, Executive Vice President, National Alliance for Hispanic Health

• Engagement: A national and/or local approach
  Melissa Creary, Assistant Professor, Department of Health Management and Policy, University of Michigan School of Public Health

• People-centered design in health
  Whitney Bowman-Zatzkin, Managing Director, Flip the Clinic

• High touch and/or high tech
  Stephen Downs, Chief Technology and Strategy Officer, Robert Wood Johnson Foundation

• Radical innovation and/or iterative improvement
  Shantanu Gaur, Co-founder, Allurion Technologies

10:00 – 10:30 AM Break
Agenda

11:00 – 1:00 PM  **Workstreams—Act I**  
Equity will be considered throughout:  
- Engagement: A national and/or local approach  
- People-centered design in health  
- High touch and/or high tech  
- Radical innovation and/or iterative improvement  

Together, the participants will explore solutions using these different perspectives as a guide. Facilitators will share their assumptions, because perspective often dictates value. In addition, we will consider long-term wins vs. short-term gains and the impact on resource allocation. Participants will determine how to best use the time over the 2 days on this topic.

1:00 – 2:15 PM  **Lunch and Plenary Presentation**  
Regina Holliday, Evocateur  
**Salon A-C**

2:15 – 3:45 PM  **Workstreams—Act II**  
Refine the solutions—what steps can we take in collaboration to solve the problems laid out in the first session?

3:45 – 4:15 PM  **Break**

4:15 – 5:00 PM  **Closing Panel: State of the Four Topics**  
**Salon D**

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**Reception and Dinner Celebration**

6:00 – 7:00 PM  **Cocktail Reception and Positive Exposure Exhibit**  
The Positive Exposure exhibit explores the social and psychological experiences of people living with genetic conditions of all ages and ethno-cultural heritages. This impressive and powerful collection of imagery and narrative celebrates the richness and beauty of human diversity and dignity.

**Salon A-C**

7:00 – 9:00 PM  **Dinner Celebration**  
We will celebrate as a community: fun, light, and uplifting! Toasts include Joan O. Weiss, Mary E. Davidson, and many friends, old and new. And, as usual, a song or two by a famous musical scientist.

**Salon A-C**
Friday, March 10, 2017

7:30 – 8:00 AM  Registration

8:00 – 9:00 AM  Networking Breakfast—Topic and Open Tables
People driving research priorities
Patient navigation
* Participants will determine other table topics

9:00 – 11:00 AM  Workstreams—Act III
Four topics and one “anarchy” session for those who don’t feel any of the topics fit them.
• **Choose a project group where you would like to put your energy.**
• **Plan this project, including goals, outcomes, and metrics.**
• **Determine where this project can flourish — which existing network or organization can lead, or do we need a new one?**

11:00 – 11:30 AM  Break

11:30 – 12:30 PM  Presentation of Solutions

12:30 – 1:30 PM  Lunch and Sign-up for Ongoing Workgroups

1:30 – 2:30 PM  Keynote Address
Reed Tuckson, Managing Director, Tuckson Health Connections

2:30 – 3:00 PM  Unveiling of the Conference Painting
Regina Holliday, Evocateur
Workstreams

**Engagement: A national and/or local approach**

Use of the term “Engagement” is ubiquitous across many disciplines. We believe that meaningful community engagement requires bi-directional communication (individuals working together) to (1) build trusting relationships and equitable partnerships, (2) work toward a common goal, (3) and be mutually beneficial to all involved stakeholders. Programs like All of Us (Precision Medicine Initiative) are national efforts. PCORnet and CTSAs are a hybrid, with a national network component and local parts. Hundreds of community efforts exist. Community engagement can be highly effective to achieve a specific or localized outcome, but can be difficult to replicate on a large scale. However, it may be difficult for people to relate to national engagement; it can run afoul of competing priorities, lack of resources, and dwindling commitment. This group will explore the balance of grassroots approaches and nationally organized movements in health. *Which methods are best for which situations? Is there a way to better link these approaches together? Can they support and be generative to each other?*

**Kickoff presenter:** Melissa Creary  
**Workstream Co-leaders:** Kathy Brill and Rebekah Angove  
**Facilitators:** Natasha Bonhomme, Andrea Goodman, Bray Patrick-Lake, and Al Richmond

**People-centered design in health**

There is a significant movement to create people and patient-centered care and participant-centered research systems, yet many of these initiatives focus on traditional parts of the system in which benefits are not accrued to the people who most need them. Rather, we need to revolutionize systems to be holistic, accountable, and economically tied to the needs of the people they are intended to serve. This session will explore what it could mean to have truly people-centered systems, ignoring existing boundaries between research and clinical care and support, and recognizing that most “healthcare” occurs outside clinics or clinicians’ offices.

**Kickoff presenter:** Whitney Bowman-Zatzkin  
**Workstream Co-leaders:** Jason Bobe and Ella Greene-Moton  
**Facilitators:** Kemp Battle, Rachael Fleurence, Michele Lloyd-Purryear, James O’Leary, and Consuelo Wilkins
High touch and/or high tech:

There is a natural inclination to focus on what is shiny and new—whether it is technology or burgeoning branches of science. Frequently it is sustained focus and relationship building that can create real, lasting change. Where are these approaches at odds and where can they work together? Participants in this session should pay special attention to resource allocation across the spectrum of research funding, business investment, and reimbursement.

**Kickoff presenter:** Stephen Downs  
**Workstream Co-leaders:** Casey Quinlan and Whitney Bowman-Zatzkin  
**Facilitators:** Nick Anderson, Matthew Harker, Crane Harris, and Kiely Law

Radical innovation and/or iterative improvement:

Whether it is quality improvement, healthcare policy change, or new systems in the development of therapies and interventions, there may be tension between or synergies in working within the system or creating a revolution. This session will explore the relative pros and cons of dramatic, radical innovation (breaking existing systems, disruptive innovation, etc.) versus iterative improvement (finding the broken parts of the system and working to fix them overtime). *What blend of each of the approaches would lead to the best results? What can we learn from other industry models? How do we identify the problems that are worth solving by either approach? How can patients help?*

**Kickoff presenter:** Shantanu Gaur  
**Workstream Co-leaders:** Usama Malik and Shantanu Gaur  
**Facilitators:** Leslie Kelly Hall, Howard Levy, Reed Tuckson, and Jennifer Wagner
**Nick Anderson**, Director of Informatics Research, UC Davis

Dr. Anderson’s research is on clinical-translational data discovery and sharing systems, patient-centered health systems, and bioethics and data sharing policy. His current focus is on personalized health and clinical integration in the context of precision health, and patient engagement through mobile technologies. Prior to his academic roles he led the development of personal health informatics software in private industry. He is chair of the UC Davis health informatics graduate program, Associate Professor in Biomedical Informatics, and director of informatics research for UC Davis Health.

**Rebekah Angove**, Engagement Director, REACHnet (a PCORnet CDRN)

Rebekah Angove serves as the Associate Director of Health Services Research at the Louisiana Public Health Institute (LPHI) where she provides leadership in the area of community and stakeholder engagement in research. Dr. Angove is the Director of Engagement for Research Action for Health Network (REACHnet, PCORnet CDRN), and PI on a PCORI-funded Engagement Award to develop medical student trainings in patient engagement and patient centered outcomes research (PCOR). With formal training and experiential expertise in community engaged research, she has worked closely with health systems to develop strategies that integrate principles of patient engagement into clinic-based research and care. She contributes her expertise to a number of clinical research projects and advisory groups including the PCORnet Engagement Committee, New Orleans Reentry Task Force, and the Tulane Preventive Medicine Residency Advisory Committee. Dr. Angove is driven by a passion to bridge the cultures of medicine, research, and community in order to build a more integrated approach to biomedical research and clinical care.
Kemp Battle, Council Member, Genetic Alliance

Kemp Battle is a catalytic change agent who works successfully with organizations and teams of all size and scope. Battle knows that good strategy is never enough. His passion is to help integrate the right team around a compelling strategy so that both team and strategy flourish. While Battle engages with teams and strategies, he also collaborates around outcomes that sustain organizational capacity and promote profitable growth. In addition, Battle has served for over two decades as a Managing Director of Tucker Capital Corp, an investment banking firm in Princeton, NJ, and continues to advise them on select matters. He also works with Leaders Quest as an Associate specializing in quests to India and South Africa. Battle has done extensive strategic work for companies as diverse as Amazon, American Council on Education, the Blair Corporation, Public Radio International, Scholastic, The Sesame Workshop and Time-Life Books; and has led multi-year acquisitions programs for domestic and international organizations. He has assisted in strategic divestitures and conceived and negotiated licensing deals, joint ventures and strategic partnerships for a number of organizations.

Jason Bobe, Co-founder and Program Director, Open Humans

Jason Bobe is Associate Professor and director of the Sharing Lab at the Icahn Institute for Genomics and Multiscale Biology at the Mount Sinai School of Medicine. As a biomedical science producer, he attempts to create research efforts that people actually want to join. He works on prototyping collaborative and participatory models of biomedical research and citizen science. With a focus on (a) greatly expanding the rates of participation in organized health research, (b) broadening the types of contributions participants in research are able to make, (c) promoting discovery & engagement through participant-centered research design and “equal access” data sharing practices, (d) the creation of well-consented public resources via the Personal Genome Project and its “open consent” framework, (e) building research networks and communities of practice around emerging technologies. At Mount Sinai, Bobe is a leader of the Resilience Project, an effort to learn how some people are protected against or recover from diseases despite being at serious risk. He is also Executive Director of Open Humans Foundation and co-founder of DIYbio.org.
Natasha Bonhomme, Vice President of Strategic Development, Genetic Alliance

Natasha Bonhomme has led initiatives in the healthcare field for over a decade, with a focus on bringing the individual and family perspectives into policy setting around newborn screening, prenatal testing, and maternal and child health overall. Since joining Genetic Alliance in 2006, she has worked to improve the state of care for families and children and currently oversees maternal and child health initiatives. As Vice President, she launched the nation’s center on newborn screening education, Baby’s First Test. In this role, Bonhomme has testified before the U.S. Senate Health, Education, Labor, and Pension Committee’s Subcommittee on Children and Families on the importance of public education for newborn screening. She serves on a range of committees including: as a Co-Chair of the Genetics and Bioethics Committee, American Public Health Association; the Association of Public Health Laboratories Committee on Newborn Screening and Genetics in Public Health; and the Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children. She currently oversees the development of the initiative Expecting Health, a central resource for pregnancy, parenting, and beyond. In 2011, she obtained a Certificate from Georgetown University in Non Profit Executive Management to better serve other non-profit partners.

Whitney Bowman-Zatzkin, Managing Director, Flip the Clinic

Whitney Bowman-Zatzkin, MPA, MSR, is a passionate community architect obsessed with connecting the dots of healthcare to provoke change for the greater good. She is the Managing Director of Flip the Clinic, a project of the Robert Wood Johnson Foundation. She started in healthcare 15 years ago as the manager of a clinical OB/GYN practice, launching its EHR, redesigning the obstetrics patient record process, and engaging in state-level advocacy efforts around maternal-infant health and malpractice reform. Moving to DC, she collaborated with policy leaders and advocates to conduct research and enact policy changes around health professions education, patient safety, primary care practice, and health workforce team design. In the past, Bowman-Zatzkin led the Great Challenges at TEDMED, and additional projects featuring her work include Scouting Health, also of RWJF; Access our Medicine, a project of Mindset Foundation and Tides Canada; and Script your Future, a grassroots medication adherence project, where she created the Team Challenge, commended by the U.S. Surgeon General and multiple Members of Congress. She holds a Master of Public Administration and a Master of Survey Research from the University of Connecticut.
Kathy Brill, Executive Director, Parent to Parent USA

Kathy Brill is Executive Director of Parent to Parent USA, serves on several healthcare and disability boards, and is mom to three daughters. Her youngest, Alexa, was born three months premature and uses numerous personal and assistive technology supports to assist her in being successfully and fully included in all aspects of her home, school, and community. In addition, her niece has Moyamoya Syndrome, a rare genetic condition, whose onset was not identified until age 10. Brill had been director of Parent to Parent of PA until 2002. Brill received the National Council on Disability 2006 Leadership Award in appreciation of outstanding contributions to the improvement of disability policy in the US. She believes strongly in the necessity of quality peer support in the building of healthy, happy families, and the possibilities of positive systems change through stakeholder collaborations. Brill holds master’s degrees in Education (certification in Special Education) and Political Management (concentration in Grassroots Advocacy).

Melissa Creary, Assistant Professor, Department of Health Management and Policy, University of Michigan School of Public Health

Melissa Creary, PhD, is an Assistant Professor in the School of Public Health, Department of Health Management and Policy at the University of Michigan. She received her PhD in Interdisciplinary Studies at the Graduate Institute for the Liberal Arts (ILA) and a B.S. in Biology and Masters in Public Health at Emory University. She served as a health scientist at the Centers for Disease Control and Prevention in the Division of Blood Disorders for nine years, where she helped create the first national program for the agency and data collection system for Sickle Cell Disease. Dr. Creary’s research and teaching interests lie at the intersection of public health, science and technology studies, and medical anthropology. She studies the social, cultural, ethical, political and historic tensions of sickle cell disease (SCD) in both the United States and Brazil. In her most recent project, she analyzes how frameworks of biology, social determinants, and policy respond to Brazilian cultural and historical ideas about race, health, identity, and legitimacy. She has been published in Genetics in Medicine, the Huffington Post, and The Journal of Bioethics, and was recognized recently by the Sickle Cell Disease Association of America with the National Champion Advocacy award.
Stephen Downs, Chief Technology and Strategy Officer, Robert Wood Johnson Foundation

Stephen J. Downs, SM, is the Robert Wood Johnson Foundation’s (RWJF) chief technology and strategy officer. In this role, he focuses on the practice of program strategy and on the alignment of the Foundation’s technology strategy and operations with its organizational directions. RWJF’s pursuit of a Culture of Health requires an approach to strategy that is highly flexible and adaptive. Downs works with his colleagues to institutionalize an approach to program strategy that is based on the integration of learning, co-creation and reflection into the processes of strategy development and ongoing strategy assessment and adaptation. Since being appointed to his current position in 2011, Downs’ goal has to been to ensure that RWJF staff have the resources they need to practice philanthropy at the highest level. He has emphasized technology directions—namely mobility and social CRM—that encourage informal knowledge-sharing, data-informed decision-making and peer-to-peer engagement. Since joining RWJF in 2002, Downs’ career at RWJF has proceeded along two parallel paths: management and programming. Along his management path, he served as the first team leader of the RWJF Pioneer portfolio, helping to shape the portfolio’s direction and initial body of work.

Adolph Falcón, Executive Vice President, National Alliance for Hispanic Health

Adolph P. Falcón provides leadership and management for the National Alliance for Hispanic Health’s program portfolio, science and policy portfolio, and development efforts. A nationally recognized expert on Hispanic health policy, he played a leading role in the landmark Disadvantaged Minority Health Improvement Act of 1990, and most recently has been active in the Children’s Health Insurance Program Reauthorization Act, Sugar-Sweetened Beverages Tax Act, Personal Care Products Safety Act, and regulatory efforts to improve quality of care. Mr. Falcón currently serves as principal investigator for the Alliance/Merck Ciencia (Science) Hispanic Scholars Program, a $4 million scholarship and internship program to increase Hispanic participation in science, technology, engineering, and math (STEM) careers. He also serves as principal investigator of Nuestras Voces (Our Voices), a cooperative agreement with the Centers for Disease Control and Prevention (CDC), working to reduce tobacco-related and cancer disparities. In addition, he is principal investigator of the Hispanic Partnership for Health Insurance Coverage, a cooperative agreement with the Centers for Medicare and Medicaid Services (CMS). He received his Masters of Public Policy from the John F. Kennedy School of Government and his Bachelor of Arts from Yale University.
Rachael Fleurence, Program Director, Research Infrastructure (PCORnet), Patient-Centered Outcome Research Institute

Rachael L. Fleurence, PhD, is a Program Director at the Patient-Centered Outcomes Research Institute (PCORI). She joined PCORI in April 2012. She leads PCORI’s initiative to build the National Patient-Centered Clinical Research Network, or PCORnet, a transformational effort to engage patients and leverage electronic health data to improve the speed and efficiency of clinical research in the United States. In this capacity, she chairs the PCORnet Executive Council and co-chairs the PCORnet Council. PCORnet is a 330-million-dollar investment involving 130 health institutions across the country and 20 patient-powered research networks. Dr. Fleurence serves on a number of Boards and Steering Committees, including most recently the National Medical Device Evaluation System Planning (NEST) Board and the SMART IRB Steering Committee. A health economist and health services researcher by training, Dr. Fleurence previously worked in the private sector outcomes research. Dr. Fleurence received a BA from Cambridge University (United Kingdom), a MA in business management from ESSEC-Paris (France), and a MSc and PhD in health economics from the University of York (United Kingdom).

Shantanu Gaur, Genetic Alliance Council and Co-founder, Allurion Technologies

Dr. Shantanu Gaur is the Founder and Chief Scientific Officer of Allurion Technologies. Together with his partners, Dr. Gaur has overseen Allurion’s research and development, fundraising, and clinical programs. He founded Allurion in 2009 to develop disruptive devices for the weight loss industry that are more effective than diet and exercise but safer, cheaper, and more accessible than weight loss surgery. Allurion’s flagship product—the Elipse™ Balloon—is the world’s first procedure-less gastric balloon for weight loss and is now available for commercial sale internationally. Dr. Gaur has overseen the development of tools and initiatives that utilize crowdsourcing and open science principles that have transformed how drugs are discovered, clinical trials are run, and healthcare data is accessed and shared. He is the lead inventor on several US and international patents and has authored multiple peer-reviewed publications. He also serves as a board member for Genetic Alliance. Dr. Gaur graduated summa cum laude with a B.S. in Biology from Harvard College and with an M.D. from Harvard Medical School where he was the Paul & Daisy Soros Fellow.
Andrea Goodman, Director of Engagement, Genetic Alliance

Andrea Goodman is a leader in public health programs and stakeholder engagement. She directs Genetic Alliance’s PCORnet Coordinating Center and oversees engagement projects and partnerships aimed at elevating stakeholder participation in health and research. She also contributes to the organization’s Expecting Health division, with a passion for re-imagining the maternity and pediatric experience in a way that meets families where they are. Prior to this role, Andrea served as Maternal and Child Health Director for the National Healthy Mothers, Healthy Babies Coalition (HMHB), where she managed content, national partnerships, and provider and consumer engagement strategy for all programs including the award-winning Text4baby service. Previous content areas include immunization and infant development, nutrition and breastfeeding, maternity care, tobacco cessation, reproductive health, and domestic violence. She holds a Master of Public Health from The George Washington University and a Master of Science in Social Work from Columbia University. Andrea is most inspired and humbled every day by her most important role as mom to two young boys.

Ella Greene-Moton, Community Liaison, Center for Public Health and Community Genomics - SPH - U of M Ann Arbor

Ella Greene-Moton has an extensive background in community organizing, advocacy, and community/academic partnership building. She currently serves as the Community Liaison at the Center for Public Health and Community Genomics – SPH, U of M Ann Arbor; the Administrator for the Community Based Organization Partners (CBOP) Community Ethics Review Board (CERB); and Community Director, Methodology Core – Flint Center for Health Equity Solutions (FCHES). In addition to serving as a “bridge” for the discussions and collaborating interactions between engaged academic institutions and the communities they serve, she serves as an Independent Community-Academic Consultant working with partnerships engaged in Community Based Public Health (CBPH) and Community Based Participatory Research (CBPR). Greene-Moton has played significant roles in establishing and/or coordinating community education opportunities by identifying potential community collaborators/partners and facilitating the local community planning discussions between the academic team and community participants. Her passion for this work is fueled by a dedication to reduce and/or eliminate health disparities and ensure health equity for underserved communities.
Leslie Kelly Hall, Senior Vice President of Policy, Healthwise

Leslie Kelly Hall combines experience as a former hospital administrator and vision as a consumer and patient advocate to fuel patient engagement in health care. As senior vice president of policy, Hall guides policy efforts for health information technology, standards, interoperability, privacy, and security that will help people engage in their health. Hall is widely recognized as a leader in health care information technology. The Office of the National Coordinator for Health Information Technology, part of the Department of Health and Human Services, has named her as Chair of the Consumer Technology Workgroup for the Health Information Technology Standards Committee. She serves on several sub committees including meaningful use, patient engagement, privacy and security, and care coordination. Her achievements in the provider market have made a significant impact on patients and physicians and on the health care system in the state of Idaho. She is the former health system CIO and VP of marketing for Saint Alphonsus Regional Health System. In 1996 she created Idaho’s first physician portal, and in 2004 her leadership was recognized through Business Week’s Top 50 Websmart Companies.

Matthew Harker, Associate Director, Duke Margolis Center for Health Policy

Matthew Harker is a project director and evaluation lead for a current CMMI Community based Palliative Care HCIA Round 2 award and End of Life portfolio of evidence generation related to the Medicare benefit. In working through the reimbursement gaps of financing both inpatient and outpatient palliative care based on physician alignment of services, there are more favorable pro-formas in care team sustainability in the post-acute care space with new CPTs to address a traditionally fragmented approach to care delivery. Harker is working on modeling value propositions from extensions of MSSP & bundling approaches to fit potential Alternative Payment Models that are consensus driven by physician groups working to align care across settings for the support of advanced life limiting illness. Harker works to extend policy relevant demonstrations to further impact readiness for the MIPS/MACRA shift of reporting, care coordination, and overall Alternative Payment Model feasibility. He received his Master’s in Public Health from the University of North Carolina, Chapel Hill, an MBA from Northwest Nazarene University, and a BS in Industrial Engineering/Psychology from Boise State University.
Crane Harris, Director of Business Development, Illumina

Crane Harris is the Director of Business Development at Illumina, where he leads strategic partnering efforts in multiple current and potential areas for application of next generation sequencing. These include transplant genomics, forensics, and clinical microbiology. Harris works closely with teams exploring the utility of whole genome sequencing to help resolve cases of rare and undiagnosed genomic disease and various population sequencing efforts around the world. For the past couple of years, he has been particularly focused on tracking and exploring means of addressing potential concerns about genomic privacy in support of important research into genomic links to health, disease, and traits. Harris received his MBA from the University of Virginia’s Darden School and has worked in business development for La Jolla Pharmaceutical Company, Monsanto, and the US Environmental Protection Agency.

Regina Holliday, Evocateur

Regina Holliday is an activist, artist, speaker and author. She is part of the movement known as participatory medicine. She and others in this movement believe that the patient is a partner with their provider and both should work together as a team. Holliday is a mother and a widow; she speaks about the benefits of health information technology and timely data access for patients due to her family loss. In 2009, she painted a series of murals depicting the need for clarity and transparency in medical records. This advocacy mission was inspired by her late husband Frederick Allen Holliday II and his struggle to get appropriate care during 11 weeks of continuous hospitalization at 5 facilities. Her paintings became part of the national debate on health care reform and helped guide public policy. Holliday also began an advocacy movement called “The Walking Gallery,” in which medical providers and advocates wear patient story paintings on the backs of business suits. This “walking wall” of 330+ individuals are attending medical conferences where often there isn’t a patient speaker on the dais or in the audience. They are providing a patient voice, and by doing so, are changing the conversation.
Kiely Law, Co-founder and Research Director, Interactive Autism Network

Kiely Law is Co-founder and Research Director of the Interactive Autism Network (IAN), a participant-powered research initiative focused on improving the lives of children and adults with Autism Spectrum Disorder (ASD). Since its launch in 2006 at the Kennedy Krieger Institute, IAN has engaged more than 50,000 individuals in ASD research. Law is the Principal Investigator for IAN’s PCORI award and is responsible for developing and implementing the network’s research activities. Advancing ASD research is both a professional and personal mission for Law. In 1996, her son was diagnosed with autism at the age of three. As the mom and caregiver of a young adult with ASD, she knows the unique value of information collected directly from those living with the struggles and triumphs of autism every day. Law received her medical and public health training at Johns Hopkins University and is a Research Associate in the Department of Pediatrics at the Johns Hopkins School of Medicine.

Howard Levy, Associate Professor of Medicine, Johns Hopkins University School of Medicine

Howard Levy is an Associate Professor in the Department of Medicine at Johns Hopkins University. He is board certified in Internal Medicine and Clinical Genetics. He specializes in primary care of adults with genetic conditions, genetic risk assessment for common multifactorial diseases, pharmacogenetics and integration of genetics into primary care medicine. He provides medical services for adults with a wide variety of genetic disorders as well as general primary care patients, with whom he emphasizes genetic principles to improve routine care and preventive medicine. Levy is particularly interested in the use of electronic health records to enhance patient engagement and the quality and efficiency of medical care. He co-chairs the Johns Hopkins Medicine committee that oversees the patient portal and other patient-facing information, sits on several additional workgroups involved in overall design of the EHR and clinical decision support initiatives at Johns Hopkins, and has worked extensively with Epic on improving management of family history and genetic data in their EHR product.
Michele Lloyd-Puryear, Consultant, Parent Project Muscular Dystrophy

Michele Lloyd-Puryear, MD, PhD, FAAP, FACMG (E) is a pediatrician and geneticist. Currently, Dr. Puryear is a consultant to Parent Project Muscular Dystrophy and the American College of Genetics and Genomics, on the steering committee of the Newborn Screening Clearinghouse, and Medical Advisor to Save Babies Through Screening Foundation. She has held academic appointments and has worked in pediatric clinics at the local and international levels. Dr. Puryear has served in an oversight and advisory capacity about genetics and newborn screening to US Department of HHS, industry, and nongovernmental organizations. She served as Special Advisor at the Office of the Director, National Institutes of Health (NIH), and as a Senior Medical and Science Advisor at the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), NIH. Over a 25-year commitment to infants, children and mothers, Dr. Puryear has made numerous contributions nationwide and internationally that have improved and expanded the quality, services and scope of the Newborn Screening System and Medical Homes for children identified through newborn screening. She is a Fellow of the American Academy of Pediatrics and an Emeritus Member of the American College of Medical Genetics and Genomics.

Usama Malik, Genetic Alliance Council Member and Innovation Catalyst

Usama Malik is the Founder and Managing Director of InnoAction Advisory Services. He has 20 years of experience doing corporate strategy, product development, new business launches, venture investing, and start-up advisory. He has worked with the Executive Teams and Boards of over 2 dozen Global 1000 companies across North America, Europe, the Middle East, and Asia. And he has had the opportunity to invest in, build, and launch over a dozen new companies for large enterprises. He has deep experience in telecoms, healthcare, digital, and technology. Malik also has significant experience with large M&A and complex operating model transformations in order to reignite new growth. Notable is his leadership on the $68b Pfizer-Wyeth merger, where he lead the post-merger integration plans that drove $4b in new [incremental] revenues, while enabling $6b in cost saving over the coming years - this is considered one of the most successful large-scale mergers in the history of M&A. In addition, Usama continues to work with a number of start-ups in New York, Washington DC, London, Capetown, and Sydney, as an angel, advisor, and growth/scaling expert.
James O’Leary, Chief Innovation Officer, Genetic Alliance

In his role as Chief Innovation Officer, James O’Leary works to foster innovation at Genetic Alliance and within its network of patients, hospitals, companies, universities, and government agencies. Over the past 10 years, James has built collaborations between these diverse stakeholders to seed change within the healthcare system and help individuals, families, and communities reclaim control of their health. He has harnessed health information and web technologies to enhance patients’ ability to access information and use that information to make better decisions. In addition, he has worked with national public health systems, disease-specific organizations, and community groups to improve access to genetic services, engage consumers in national policy-setting, and institute legislation that protects the public from discrimination. James earned an MBA from the Wharton School of the University of Pennsylvania and a BS in Biology, concentrating in Cellular and Molecular Biology and Genetics from the University of Delaware.

Bray Patrick-Lake, Director of Stakeholder Engagement, Duke CTSI

Bray Patrick-Lake supports efforts to actively engage patients, health advocacy organizations, and other stakeholders in Duke University’s local and national research programs. She has led extensive efforts through the Clinical Trials Transformation Initiative to incorporate patient voice into clinical trial design, conduct, oversight, and regulatory frameworks, as well as improvement of the clinical trial enterprise. She co-chaired the Advisory Committee to the NIH Director’s Working Group responsible for authoring the vision and roadmap to launch the Precision Medicine Initiative Cohort Program. Bray served as the Interim Director of Engagement for several months after launch of the cohort program, now known as the All of Us Research Program. She currently serves on the All of Research Program National Advisory Panel, leads engagement work at Duke’s Coordinating Center for NIH’s Environmental Influences on Child Health Outcomes (ECHO) program, and supports engagement efforts for Verily’s Baseline study.
Casey Quinlan, Precision Medicine Advocate, Cure Forward Corp; the Mighty Mouth, Mighty Casey Media LLC

Casey Quinlan covered her share of medical stories as a TV news field producer, and used healthcare as part of her observational comedy set as a standup comic. So when she got a breast cancer diagnosis five days before Christmas in 2007, she used her research, communication, and comedy skills to navigate treatment, and wrote “Cancer for Christmas: Making the Most of a Daunting Gift” about managing medical care and the importance of health literate self-advocacy. In addition to her ongoing work as a journalist, she’s an active member of the Society for Participatory Medicine, a contributing editor to SPM’s e-patients.net blog, a Precision Medicine Advocate for Cure Forward, and part of the Lown Institute’s Right Care Alliance. Quinlan is part of the HealthIT.gov Consumer Empowerment Workgroup of the Health IT Policy Committee (HITPC), and an ePatient Scholar to Stanford’s MedicineX. Over the past several years, she participated in the development of the Patient and Family Engagement Roadmap, was recognized as a patient engagement expert by the WHO, and presented at conferences worldwide, serving as a patient voice on topics from trust in the clinical relationship to data security issues in medical record interoperability.

Al Richmond, Executive Director, Community-Campus Partnerships for Health (CCPH)

Al Richmond, MSW, has a career that has uniquely blended social work and public health to address racial and ethnic health disparities. As an international community health leader, Richmond advocates for transformative partnerships to address the most critical issues facing our society. As a founding member and past chair of the Community Based Public Health Caucus and the National Community Based Organization Network, he helped to foster effective partnerships focused on community-identified health concerns while increasing the number of community leaders actively involved in the American Public Health Association. He has engaged in research partnerships to build coalitions, disseminate health information, and develop training modules. A past CCPH Board Member, Richmond served as planning committee member and speaker for CCPH’s three National Community Partner Forums on Community-Engaged Research, contributing to the development of the Community Network for Research Equity and Impact. He is Principal Investigator of the Patient-Centered Outcomes Research Institute (PCORI) funded project, “Facilitating Community Engagement through Partnerships.” He holds a Bachelor of Social Work degree from Livingstone College and Master in Social Work from The Ohio State University.
Joe Selby, Executive Director, Patient-Centered Outcomes Research Institute

After obtaining his MD Degree from Northwestern, Dr. Selby moved to Northern California for an internship and a family medicine residency and eventually an MPH at UC Berkeley. His fellowship project concerned Behavioral Factors in Cardiovascular Disease. He stayed in the Bay Area at Kaiser Permanente for 27 years, including 13 as Director of Research supervising up to 50 investigators and 500 staff members. He has had academic appointments at UC Berkeley, UCSF and Stanford. Dr. Selby has authored more than 200 peer reviewed articles on far ranging topics such as quality measurement and improvement, primary care delivery, colorectal cancer screening and many studies that could be classified under the heading of “comparative effectiveness” – largely in the areas of diabetes, HTN and cardiovascular disease. He has received honors from the Public Health Service, the American Epidemiological Society, Kaiser Permanente and in 2009 he was elected into the Institute of Medicine. In July 2011, Dr. Selby became the first Executive Director of the Patient-Centered Outcome Research Institute (PCORI). PCORI’s mandate is to improve the quality and relevance of the evidence available in order to help patients, caregivers, employers, insurers, and policy makers make informed healthcare decisions.

Reed Tuckson, Managing Director, Tuckson Health Connections

Reed V. Tuckson, MD, FACP, is Managing Director of Tuckson Health Connections, LLC, a health and medical care consulting business that brings people and ideas together to promote optimal health outcomes and value through innovation and integration across the fields of prevention; public health; consumer activation; quality care delivery; the translation of science and technology into value producing interventions; and optimization of big data and analytics. Previously, he served as Executive Vice President and Chief of Medical Affairs for UnitedHealth Group; Senior Vice President for Professional Standards of the AMA; Senior Vice President of the March of Dimes Birth Defects Foundation; President of the Charles R. Drew University of Medicine and Science; and Commissioner of Public Health for the District of Columbia. Tuckson is a graduate of Howard University, Georgetown University School of Medicine, and the Hospital of the University of Pennsylvania’s General Internal Medicine Residency and Fellowship Programs, where he was also a Robert Wood Johnson Foundation Clinical Scholar studying at the Wharton School of Business.
Jennifer Wagner, Associate Director of Bioethics Research, Geisinger Health System

Jennifer K. Wagner, JD, PhD, is Associate Director of Bioethics Research and Assistant Professor in the Center for Translational Bioethics & Health Care Policy at Geisinger Health System and is a licensed, practicing attorney. She earned her JD at the University of North Carolina and her PhD in Anthropology at the Pennsylvania State University before completing post-doctoral research appointments at Duke University’s Institute for Genome Sciences & Policy and the University of Pennsylvania’s Center for the Integration of Genetic Healthcare Technologies. Dr. Wagner has a K99/R00 “Pathway to Independence Award” from the National Human Genome Research Institute to conduct a “multidisciplinary study of race, appearance, ancestry, discrimination, and prejudice.” At Geisinger she contributes to efforts to strengthen patient-centered care and participant-centered research, is a co-facilitator of a Precision Health Participant Advisory Board, and leads a Social Media in Research Working Group. Prior to joining Geisinger, Dr. Wagner served in a US Senator’s office in Washington DC as a 2014-2015 AAAS Science & Technology Policy Congressional Fellow, where she managed the judiciary portfolio and assisted with privacy, health, consumer protection, and environmental policy. Dr. Wagner is on Twitter @DNAlawyer.

Consuelo Wilkins, Executive Director, Meharry-Vanderbilt Alliance

Consuelo H. Wilkins, MD, MSCI, is a physician, biomedical researcher and current Executive Director of the Meharry-Vanderbilt Alliance. Dr. Wilkins holds faculty appointments as Associate Professor of Medicine at both Vanderbilt and Meharry and is widely recognized for her innovative work in community engaged research. Dr. Wilkins is the current principal investigator (PI) of more than $25 million in research awards including funding from the Patient-Centered Outcomes Research Institute and NIH. She has pioneered methods of stakeholder engagement that involve community members and patients in research across the translational spectrum. Engaging communities in research is a key strategy in Dr. Wilkins’ health equity research and is deeply embedded in her work as a PI of the Vanderbilt-Miami-Meharry Center of Excellence in Precision Medicine and Population Health, which focuses on decreasing disparities among African Americans and Latinos using precision medicine, and the Vanderbilt Recruitment Innovation Center, CTSA-wide center dedicated to enhancing recruitment and retention in clinical trials. As leader of the Meharry-Vanderbilt Alliance, Dr. Wilkins oversees a portfolio of cross-institutional initiatives in three pillars: community health and engagement, translational research, and interprofessional education.
Regina Holliday is an activist, artist, speaker, and author. You might see her at a health conference painting the content she hears from the patient view. She is part of the movement known as participatory medicine. She and others in this movement believe that the patient is a partner with their provider and both should work together as a team.

Regina is a mother and a widow; she speaks about the benefits of health information technology and timely data access for patients due to her family loss. In 2009, she painted a series of murals depicting the need for clarity and transparency in medical records. This advocacy mission was inspired by her late husband Frederick Allen Holliday II and his struggle to get appropriate care during 11 weeks of continuous hospitalization at 5 facilities. Her paintings became part of the national debate on health care reform and helped guide public policy.

She also began an advocacy movement called “The Walking Gallery.” The Gallery consists of medical providers and advocates who wear patient story paintings on the backs of business suits. Paint and patients, pills and policy all come together within The Walking Gallery of Healthcare. This “walking wall” of 400+ individuals who wear personal patient narrative paintings on their backs is changing minds and opening hearts. They are attending medical conferences where often there isn’t a patient speaker on the dais or in the audience. They are providing a patient voice, and by doing so, are changing the conversation. She published a book with the Health Informatics Society of Australia (HISA) in 2012 entitled: “The Walking Wall: 73 Cents to the Walking Gallery.” She was recently appointed as a judge for HIMSS’ 2016 Most Influential Women in Health IT Awards.

**Top:** Hatching

**Left:** The Way the Wind is Blowing

**Right:** If the Shoe Fits
Celebrating the beauty of genetic diversity.

Rick Guidotti, an award-winning photographer, has spent the past twenty years collaborating internationally with advocacy organizations/NGOs, hospitals, medical schools, universities and other educational institutions to affect a sea-change in societal attitudes towards individuals living with genetic, physical, behavioral or intellectual difference; his work has been published in newspapers, magazines and journals as diverse as Elle, GQ, People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, the Washington Post, Atlantic Monthly and LIFE Magazine.

Rick is the founder and director of Positive Exposure, an innovative arts, education and advocacy organization working with individuals living with genetic difference of all ages and ethno-cultural heritages. Positive Exposure utilizes the visual arts to significantly impact the fields of genetics, mental health and human rights, by providing new opportunities to see an individual living with a difference, first and foremost as a human being, rather than as a specific diagnosis or disease entity.

The Positive Exposure photographic exhibition premiered at the People’s Genome Celebration at the Smithsonian’s National Museum of Natural History in June 2001 and remains committed to exhibiting in galleries, museums and public arenas internationally. Positive Exposure continues to create and display ever-evolving community based exhibitions around the world. These collections of images, film and narratives celebrate the richness and beauty of human diversity.

www.positiveexposure.org
Positive Exposure has recently introduced FRAME: (Faces Redefining the Art of Medical Education). FRAME is a web-based library of brief films and photographic galleries that change how medical information is presented to health care professionals in training, clinicians, families and communities. In each FRAME film, individuals living with the featured condition and their families demonstrate the basic hallmark characteristics of the condition, placing humanity front row and center in medical education.


"The usual depictions of these conditions reduce people to clinical anonymity. Rick SEEs the beauty in everyone, gives expression to the individual’s heart and soul, and exquisitely captures it in his photographs. This book conveys the marvel of the human body and spirit, in all forms."

-SHARON TERRY, GENETIC ALLIANCE
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CONGRATULATIONS TO GENETIC ALLIANCE ON 30 YEARS OF OUTSTANDING HEALTH ADVOCACY!
**Key Facts About ME/CFS**
(*myalgic encephalomyelitis/chronic fatigue syndrome*)

- An estimated 836,000 to 2.5 million Americans have ME/CFS
- 25% of ME/CFS patients will become bedbound or housebound in their lifetime
- Up to 91% of patients are undiagnosed; nearly all are initially misdiagnosed
- The cause of ME/CFS is unknown
- There are NO FDA-approved treatments

**Our Work**

**IMPROVE THE ME/CFS ECOSYSTEM THROUGH RESEARCH, ADVOCACY, AND PUBLIC POLICY**

**ENABLE PATIENTS’ PARTICIPATION IN FINDING SOLUTIONS AND CURES**

**ACCELERATE THE DISCOVERY PROCESS**

**CONDUCT ORIGINAL RESEARCH AND FUND MERITORIOUS IDEAS**

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**We Are**

- Members of the Genetic Alliance Registry and Bio-Bank: a disease advocacy-driven research solution
- Recipients of the Genetic Alliance/RWJF PEER white label award: an empowering platform for patient participation in research and medical information

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**PRESIDENT AND CEO CAROL HEAD**, an ME/CFS patient herself, earned her MBA from Stanford University. She was recently named a 2017 Health Hero by *O, The Oprah Magazine*.

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**CSO AND VICE PRESIDENT FOR RESEARCH ZAHER NAHLE, PHD, MPA**, earned his PhD in physiology and biophysics from Cold Spring Harbor Laboratory/SUNY-SB and his MPA from Harvard University. He is an awardee of the AHA and the DoD and was a Mason fellow at the Harvard Kennedy School.

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**Contact Us**

Solve ME/CFS Initiative
5455 Wilshire Blvd.
Suite 1903
Los Angeles, CA 90036
(704) 364-0016
www.SolveCFS.org
SolveCFS@SolveCFS.org
SolveMECFSInitiative
@PlzSolveCFS
Congratulations to the Genetic Alliance on 30 Years of Making a Difference.

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