Welcome

Every day, individuals attempt to navigate the complex healthcare landscape to achieve better well-being for themselves and their families. We face the challenge of a healthcare marketplace that is not built around real needs; at best cobbling together a suite of providers and resources, and at worst, reduced to nameless data, files, and a list of symptoms. Barriers exist where roads could be open. People are seen as “patients” or “subjects” rather than experts, leaders, and valuable contributors. In order to create a research and healthcare system that works for all involved, we must truly value people, their perspectives, and their needs, while engaging them as partners. But envisioning a holistic solution requires all existing stakeholders to step out of their silos and collaborate. On March 9-10, 2017, together with peers and friends from diverse backgrounds in healthcare, medical research, and patient advocacy, Genetic Alliance celebrated the successes, examined the failures, and—most importantly—planned for a future that prioritizes the health of individuals, families, and communities.
Mission

 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 so that they respond to what people need most. We convene powerful networks, deliver actionable information, build intuitive tools, and drive policy decisions.
# Values

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

<table>
<thead>
<tr>
<th>Values</th>
<th>Description</th>
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<tbody>
<tr>
<td>Collectivity</td>
<td>We believe that everyone values health and well-being for themselves and those they love.</td>
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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, me must also risk our comfort and be willing to trust in others,</td>
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<tr>
<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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<tr>
<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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<tr>
<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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Context

We kicked off our most collaborative and participatory conference to date with a risky collective activity. Genetic Alliance’s CEO, Sharon Terry, led more than 200 meeting participants in a mindfulness exercise in which each person silently followed their breath for five minutes. Following this centering exercise, each person chose a partner and engaged in a repeating inquiry exercise, crafted to prepare us to be truly present with deep listening and openness beyond our usual reactions. With no interruption for five minutes, we took turns listening to each partner’s response to the question: “Tell me what you need to listen deeply?” This forum for speaking, without interruption, as slowly as needed, and into wide open space, was a phenomenal way to open participants to showing up fully for one another.

The purpose of this engagement was not to sit and listen, but to open to new perspectives from diverse stakeholders, and engage in the co-collaboration with the intention of driving toward actionable goals.

With more than 200 individuals in attendance, representing many viewpoints and experiences within the participant, patient, caregiver and healthcare sectors, Genetic Alliance set out to create an atmosphere of open heart and open mind. The body of the meeting offered four unique work streams:

- **Engagement:** National and/or local
- **People-centered design in health**
- **High touch and/or high tech**
- **Radical innovation and/or iterative improvement**

Participants were invited to leave all biases at the door and engage in openness. Over the course of two days, using these four focus areas and an option to step out into a free-form session, participants discussed, debated, and defined opportunities and challenges for individuals to take charge of their health and catalyze the answers they seek. Mindful of the marching orders to bring solutions, meeting participants did not focus on plowing old ground or griping about the problems. Each stream came up with projects that had legs well beyond the conference.
Divided into three Acts, participants explored, refined, and narrowed their focus on the varying topics under discussion.

**In the first Act**, participants explored solutions by sharing different perspectives. Facilitators revealed their assumptions about the topic to highlight the challenge to overcome. The groups considered long-term wins vs. short-term gains and the impact on resource allocation.

**In the second Act**, participants refined their solutions and collaborated on identifying steps to solve the problems laid out in the first session.

**For the final Act**, participants narrowed their focus, choosing a group project and collaboratively mapping out goals, outcomes, and deliverables to give their project a strong opportunity for flourishing.

Thanks to the efforts of Whitney Bowman-Zatzkin and the Flip the Clinic team, facilitators were provided with a number of resources to assist in creating a dynamic, engaging environment for workstream sessions. See examples on the next page.
The Check-In gives each participant a turn to briefly share what’s happening in their world—what they are thinking, feeling, and wanting at that moment. Sharing openly and immediately provides each member with a chance to have their feelings acknowledged by the group, so they’re able to “get it out” and set preoccupying thoughts aside. Others practice how to listen empathetically, suspend judgment, and create a safe space where each member can share their authentic feelings and thoughts.

Writing in a journal is a key component of learning by experience. By noticing, reflecting, and documenting how ideas evolve or a prototype design is tested over time, journaling can help us get a clearer emotional grasp on a project. It helps project stakeholders articulate how their understanding has evolved, and it provides a solid foundation for deciding the next steps for an idea, prototype, or project.

A Flip is an idea that fundamentally shifts something about the patient-clinician encounter—a process, an interaction, a technology—so that it works better for patients, clinicians, or both. It’s something that is explainable and shareable. With community feedback and testing, a Flip is an idea that will grow, increasing effectiveness and impact over time.
Engagement: National and/or local

Key Takeaways
The value of “engagement” is ubiquitous across many disciplines. Meaningful community engagement requires bi-directional communication (individuals working together to (1) build trusting relationships and equitable partnerships, (2) work toward a common goal, and (3) be mutually beneficial to all involved stakeholders. But effective communication can be very different depending upon the program in question. 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. Engagement on the national level is most effective at raising awareness but can face challenges in implementation because of competing priorities. Local engagement is most effective when trying to achieve single, localized goals but rarely has the combined voice needed to bring attention to the national level.

These ideas led participants to seek a unified solution that could be used at any level of engagement. What would a unified standard of engagement policy to bridge the gap between local and national engagement look like?
Proposed Projects

Engagement - Good Housekeeping Seal of Approval

- Provide support for groups actively participating in engagement
- Do not prescribe which methodology to use
- Raise visibility of engagement
- Define and find best practices


Central Platform to Coordinate Collaboration
Across Organizations and Platforms

- One-stop shop where stakeholders can search all resources, organizations, and research projects
- Create connections across multiple organizations for research and resource-sharing
- Simplify access to information and organizations
- Help organizations understand evolving landscape of engagement
- Increase transparency around funding and access to communication and data

Pilot – Have a central platform to coordinate collaboration with organizations and their products
People-centered design in health

Key Takeaways
A significant movement to create patient-centered care and participant-centered research systems persists, 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. It is people who need to be part of the conversation, not just the participants. For patient-centric care to be successful and for the system to function properly, it is crucial that everyone involved must identify as both givers and receivers. What does prevention look like from a people-centered perspective? Attendees envisioned solutions that would put individuals and families in control.

Proposed Projects

Create a secure, portable database owned by the people

- Research-available vehicles already in place
- Modified by the individual owning the data
- Survey networks to see who desires to have access and control of their data
- Pilot programs to enact this owner shared data

Create a preamble to define how every healthcare process should start

- Principles behind every healthcare process should start by asking questions
  - What makes us human?
  - What brings us together?
- Focus on how every healthcare process should start
Key Takeaways

Whether technology, new products, or burgeoning branches of science—we’re naturally inclined to focus on what is shiny and new. Yet we know that frequently, it is sustained focus and relationship building that can create real, lasting change. Participants and their dependents should be making executive decisions but ultimately aren’t given the power or ability to translate the information given to them by healthcare professionals.

In this work stream, attendees focused on methods to help clinicians and researchers to communicate clearly and concisely with participants. Language barriers and technological literacy were considered. How can organizations and individuals manage the technology that is becoming more prominent in the world of healthcare? How can advancements be made without the loss of personal contact?
## Projected Projects

### Consent R Us
Pilot – Create central repository of consents; individuals can control consent/use of data from one location

### Crack the Worries
Pilot – Create tool that patients can use prior to a genetic counseling visit to identify their concerns; the provider can review it and address all concerns during the visit

### Patient Speak
- Re-develop relationships with clinicians would rapidly validate PROs
- Seek to address the problem of patient reported outcomes data not being recognized as validated data

### The Price Ain’t Right
Pilot - Take existing data journalistic projects such as ProPublica and Clear Health Cause and integrate them with industry/policy projects; start public campaign where people post the price they pay and explanation of benefits to create more transparency around cost

### Side-by-Side
- Currently EHR blocks patient-clinician interaction
- Use big screen that patients and clinicians can look at together and talk through the data
- Also enable patient curation – patients fix and contribute to information as it is being written
- Pilot by finding a site that uses open notes.
Radical innovation or iterative improvement

Key Takeaways
Whether it is quality improvement, healthcare policy, or the development of therapies and interventions, it can be difficult to determine the correct path to change. Do we work within the system or try to seed a revolution?

Attendees identified an area where they felt both were needed. Namely, when it comes to healthcare and disease information, people feel alone. Needs and the resources available vary. The system is complex. Clinicians often feel overwhelmed and are not available for people with specific needs or rare disorders.

Making sure individuals feel connected, included, and looked after would ensure comfort and therefore increase connectivity. A paradigm shift could occur if system project managers or care coordinators were widely used to assist with access to healthcare, supporting the community, aligning incentives, translating information, and making data available. There are many communities available to a participant—medical, disease, health, and faith groups. These communities need time, money and resources to offer care, wellness information, legal help, research, evidence, navigation, care coordination, and tools.
Prosposed Projects

My Communities

• Improve the quality of life for patients, families, and caregivers creating communities
• Map out a landscape of the community, social/emotional needs, and focus on geography and quality of life
• Launch pilot (most likely in the rare disease community because they are narrow, but passionate)

Data ≠ Information ≠ health

• Address the problem that data does not necessarily lead to information
• Be transparent about data limitations
  o Especially when the data is being used to answer another question beyond the original research question
  o Consider the possibility of original data containing existing biases
• Use Twitter to draw attention to when data is not being used appropriately or there are existing biases
• Have a patient representative on boards and give representatives voting rights
• Start bond portfolio with various stakeholders and distribute risks for drug development.

Interoperability Hub

• Create better operability among stakeholders
• Have stakeholders be better data stewards.
• Create a hub made up of various stakeholders
• Pilot using high-cost, radiological tests
Celebrating Legacy

In addition to “Co-creating a Healthy Future,” Genetic Alliance and guests spent the first evening of the conference celebrating 30 years of excellence and the individuals who made that possible. No organization reaches such a milestone without strong leadership. Genetic Alliance has been graced with three incredibly strong leaders over the decades: Joan Weiss, Mary Davidson, and Sharon Terry.

Celebrations included toasts to these leaders and community who helped guide Genetic Alliance through its 30 years; a formal dinner; and special presentations.

One such special guest was founder of Positive Exposure, Rick Guidotti, who shared his experiences photographing individuals with rare genetic conditions and how the simple act of taking someone’s picture can help instill confidence. Rick spoke passionately about replacing the lens through which we see genetic conditions—instead of looking at a person and seeing their condition, we should be seeing the beauty of the individual. As a special surprise, Rick donated several copies of his book, “Change How You See, See How You Change” to conference attendees.

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 narrative celebrate the richness and beauty of human diversity.

To close the evening’s festivities, Francis Collins—Director of the National Institutes of Health—shared kind remarks about how he came to know Genetic Alliance and the work accomplished in tandem. At the end of the night, Dr. Collins treated guests to a performance of classic American folk songs, repurposed for Genetic Alliance.
Painting the Conference

Regina Holliday, founder of the Walking Wall, 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. Drawing from her own experiences in dealing with loss, Regina attends health conferences and paints what she hears from the patient’s perspective.

In addition to creating an original piece of artwork commemorating our conference, Regina shared the story of her late husband, Frederick Allen Holliday II, and his struggle to receive appropriate care during 11 weeks of continuous hospitalization at five facilities. Her story and her paintings did more than just move the packed room to tears; they have become part of the national debate on healthcare reform and are helping guide public policy.
Closing Address

As the conference drew to a close, Dr. Reed Tuckson delivered a closing address with a strong message. “We must create a shared vision for health and it begins inside of us.” His remarks hammered home the impact of the conference – the fight for humanistic, holistic, equitable, and quality health and medical care.

Dr. Tuckson asked those in attendance to be the change we wish to see. Reminding us it is the individual that we are meant to help – that we must ask them about their goals and their definition of success.

Working for Tomorrow

For two days, we took a breath together, slowing down to ponder 30 years of glorious work by our community in advocacy, policy, technology, and education,

For two days, we jointly asked hard questions. Not resting on our laurels, at every major anniversary Genetic Alliance brings our community together to ask, “Does the world still need us?” “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?”

For two days, we invested our comfort, moving beyond what is familiar, to experiment with how we can alleviate suffering, support health, and further well-being. For two days, we united as a community of diverse stakeholders. We did this with a very real urgency, for those who cannot take the steps we can—sometimes quite literally.
Thank you to our generous sponsors. Without their support and partnership, this meeting and its learnings would not be possible.

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In Closing

Galvanized by the work streams described above, attendees joined the ongoing projects outlined and brainstormed new approaches to be used within their own communities. Renewed in purpose, attendees took the incredible energy and vision co-created in those conference rooms and began channeling it into proactive approaches to change the world. As we said our farewells, individuals and conversations carried onward and out into the world, full of optimism, and a desire to improve their community’s health. These community efforts are the backbone of change. It is through their will and determination that the barriers between healthcare and people will come crashing down. With three decades behind us, we take the ideas and passion of our community with us as we vision our role in co-creating a healthy future over the next 30 years.