**RG Mission Statement Discussion**

Please see the below summary of the 2016`06`05 Rare Genomics Institute Executive Staff Meeting discussion on the modification of the Mission statement.

This document includes a summary of the purpose of the meeting, the purpose/intent of a mission statement, excerpts from the conversation, our current mission statement, and the evolution of ideas to form consensus for the new mission statement. Please review the document and provide input, updates, and corrections as necessary. For your convenience, Mission Statements and Mission Statement ideas, are highlighted in yellow.

We will compile the information into a working document and present to the team for final adoption.

We will be taking a good amount of time discussing and interacting on the Vision and Mission of RG. As our growth continues it's important to reassess the statement that defines all our activities and objectives. Without a clear understanding of the vision we will individually make decisions that seem best for the time. As a leader, recasting the vision is a constant and continually activity that keeps all our people motivated and aligned.

Paul Schindler

In support of enhancing organizational culture, we want to ensure that we have a mission statement that is clear and specific. We want our volunteers, families, and potential partners to be aware of our purpose. As the HR team interviews potential volunteers, they are often asked about the mission, although they can easily describe what RG is about, we do not currently have a full mission statement.

Russell Davis

Definitions - (working definitions from BusinessDictionary.com)

* [Mission](http://www.businessdictionary.com/definition/mission-statement.html#ixzz48wLmWKpJ) - A written declaration of an organization's core purpose and focus that normally remains unchanged over time. Properly crafted mission statements (1) serve as filters to separate what is important from what is not, (2) clearly state which markets will be served and how, and (3) communicate a sense of intended direction to the entire organization. A mission is different from a vision in that the former is the cause and the latter is the effect; a mission is something to be accomplished whereas a vision is something to be pursued for that accomplishment.

Our current Rare Genomics Institute Mission statement:

* “We are a community dedicated to helping rare disease patients find hope for a cure.” <http://www.raregenomics.org/our-mission/>

The purpose of a mission statement is to give a concise explanation of the business's reason for existing and its long-term goals. The HR team did a brainstorming exercise and came up with a number of ideas, but the statement with the best potential was from Laura Barrera:

* To improve rare disease diagnostics and therapy via cutting edge research working with scientists across the globe. We help individual patients understand and [or] find a path to treatment for their rare diseases.

Executive Team members had the following comments:

**Daniel –** The current mission statement as well as some of our organizational statements in support of our current mission statement [ namely our organizational values as stated on the website - Dedicated to Overcoming Barriers, A Culture of Caring, Focused on the Individual, Organizational Transparency, and Tangible Results] do not meet the criteria of the definition and purpose of a mission statement, and the value statements are vague and or seem to offer an apology for how we work to support our mission. Laura’s suggestion is a good start. In addition, here is what we share during our international calls – **Rare Genomics helps to facilitate patient outcomes. By getting an actual biomarker it reduces the amount of guesswork for clinical care for patients - It reduces mistreatment.**

**Sarah –** let’s start with what the Grants team uses:

(Sarah) This (or a slight derivative) is what the FG&IR uses as RG’s mission statement for our grants:

**Mission statement -** In one sentence, describe your organization's mission.

RG is a community dedicated to helping rare disease patients find hope for a cure.

**Mission statement** - 50 words maximum:

Rare Genomics Institute believes every child should have the hope of a healthy life, because every disease will be treatable - no matter how rare. Our mission is to establish a new paradigm of patient-empowering, personalized medicine that accelerates rare disease cures by providing knowledge, human resources, capital, and scientific tools.

**Ray** - Rare Genomics is dedicated to helping rare disease patients live better lives through sharing information and individual advocacy.

**Nolin** - Rare Genomics Institute is a non-profit biotech venture that enables genome sequencing primarily for children with rare and or orphan diseases. Our mission is to help these patients find diagnoses, treatment, and cures. We connect expert scientists with families to utilize the most advanced technologies to diagnose and accelerate research for their children. We provide access to an innovative funding mechanism called crowdfunding, where many people donate small amounts, to help families with the cost of sequencing.

**Nolan –** Is there a better way to define the outcome? Also, in developing the current suggestion for a mission statement did HR look at the previous strategic planning document before you asked this?[Russell’s response, “No we did not review the strategic planning document.]I will forward the link to the Exec Committee for review.

**David –** It is important to add the Rare Genomics is a non-profit organization. We must let volunteers, perspective volunteers, clients/families, sponsors, partners, etc., know what are we in the business to do. We should star the mission statement with, **“We are a non Profit”**

**Josef** – We need to be as specific as possible and state that we are a 501C3 charitable tax exempt non-profit organization.

**Romina** – Rare Genomics helps families understand [diagnosis] and then help with research.

**Eva** – are we doing research or are we providing opportunities to others [to do the research]? Rare share, science 2.0, etc. Are we doing what this current mission statement says? What is the best course for the organization?

**Paul** – we are in transition, but our mission statement can be aspirational and state what we do as well as what we want to do…. We need to define RG in a sense that is marketable, manageable - also discussed the Vision – a BHAG [Big Hairy Audacious, Goal]. Paul originally talked with team members about setting a vision or stating that our mission could be to cure all diseases through genetic research…. But this made some uncomfortable – and struck some with trepidation. Remember that JFK made a statement/challenge in 1961 to put a man on the moon within 10 years. The role of leadership is to dream big and set the vision/mission even if we do not know how to reach it – this gives everyone something to strive for and puts the best minds to work to reach the mission/vision. Don’t be afraid to dream big.

**Richard** - …we don’t really actually get involved in diagnostics or treating patients – we do a lot of patient advocacy which is lacking in the rare disease space. The second part of RG’s statement is to help them understand the information that they receive and having a team that can support them. So many patients go through dozens of doctors and that is the reason so many come to us…. with Rareshare and Rare Genomics we are key resource with the *knowledge sharing community* – we bring knowledge to the rare disease world. Jimmy started RG with this purpose. With the RDTF, Ask the experts, and BeHeard, we are an enabling platform that aggregates all the stakeholders on a platform to empower the patients to know what their resources are. We are moving in the right direction with the products we are creating – Science 2.0 Rareshare, BeHeard etc., are on the right track to help ensure that our goals are aligned with the mission.

**Laura** – The mission doesn’t need to include the different programs of the organization. It’s all about what we are after, what we are trying to do. Maybe we are not doing direct [diagnostic or therapy development] – but we want to improve those things by doing what we do, by the platforms we use, by the product we create. The mission needs to be general to allow opportunities for growth, creativity and innovation. The fact that there are certain things that we don’t/aren’t doing now shouldn’t hold us back from dreaming.

**To improve rare disease diagnostics and therapy via cutting edge research working with scientists across the globe. We help individual patients understand and [or] find a path to diagnostic and treatment for their rare diseases.**

**PAUL -** Do we craft the mission statement based on the needs that we know are out there? RG provides some of the core issues we have discussed this evening; patient guidance, expanding knowledge, accelerating knowledge, treatment and ultimately finding cure. Our current teams are engaged in these tasks:

* **Guidance - They need guidance – Romina’s Team**
* **expanding the knowledge – BeHeard and Science team/Rare Reach**
* **accelerating knowledge, treatment and cure – Communications, BeHeard and Science team/Rare Reach**

**Nolan** – Creating a mission statement is a big deal. Let’s think about what we can accomplish tonight – and then look at all the other pieces – This is a big ask to do. When we did this last time it took a while and was a big deal.

**Eva** – can you send the strategic planning document to everyone? [Nolan – yes – see below]

* **Rare Genomics Institute is a non-profit biotech venture that enables genome sequencing primarily for children with rare and orphan diseases. Our mission is to help these patients find diagnoses, treatment, and cures. We connect expert scientists with families to utilize the most advanced technologies to diagnose and accelerate research for their children. We provide access to an innovative funding mechanism called crowdfunding, where many people donate small amounts, to help families with the cost of sequencing.**

A compilation of all ideas leads to the following draft document:

* Rare Genomics helps to facilitate patient outcomes. By getting an actual biomarker it reduces the amount of guesswork for clinical care for patients - It reduces mistreatment.
* RG is a community dedicated to helping rare disease patients find hope for a cure.
* Rare Genomics Institute believes every child should have the hope of a healthy life, because every disease will be treatable - no matter how rare. Our mission is to establish a new paradigm of patient-empowering, personalized medicine that accelerates rare disease cures by providing knowledge, human resources, capital, and scientific tools.
* Rare Genomics is dedicated to helping rare disease patients live better lives through sharing information and individual advocacy.
* Rare Genomics Institute is a non-profit biotech venture that enables genome sequencing primarily for children with rare and or [undiagnosed] diseases. Our mission is to help these patients find diagnoses, treatment, and cures. We connect expert scientists with families to utilize the most advanced technologies to diagnose and accelerate research for their children. We provide access to an innovative funding mechanism called crowdfunding, where many people donate small amounts, to help families with the cost of sequencing.
* To improve rare disease diagnostics and therapy via cutting edge research working with scientists across the globe. We help individual patients understand and [or] find a path to treatment for their rare diseases.
* we are a 501C3 charitable tax exempt non-profit organization.
* helps families understand [diagnosis] and then help with research.
* to cure all diseases through genetic research
* to help them understand the information that they receive and having a team that can support them.
* we bring knowledge to the rare disease world.
* To improve rare disease diagnostics and therapy via cutting edge research working with scientists across the globe. We help individual patients understand and [or] find a path to diagnostic and treatment for their rare diseases.
* Rare Genomics Institute is a non-profit biotech venture that enables genome sequencing primarily for children with rare and orphan diseases. Our mission is to help these patients find diagnoses, treatment, and cures. We connect expert scientists with families to utilize the most advanced technologies to diagnose and accelerate research for their children. We provide access to an innovative funding mechanism called crowdfunding, where many people donate small amounts, to help families with the cost of sequencing.

**Below is a first draft of a new statement incorporating key elements from the afore mentioned discussion and mission statement ideas:**

The Rare Genomics Institute is a 501C3 charitable tax exempt non-profit organization dedicated to *[helping patients live better lives by]* enabling genome sequencing to improve rare disease diagnostics, therapy, treatment, and accelerate cures. We are dedicated to establishing a new paradigm of patient-empowerment *[to help families with the cost of sequencing],* through crowdfunding, cutting edge research, and personalized medicine by providing knowledge, human resources, capital, and scientific tools through/in collaboration with scientists from across the globe.

Or (with the yellow italicized text removed)

The Rare Genomics Institute is a 501C3 charitable tax exempt non-profit organization dedicated to enabling genome sequencing to improve rare disease diagnostics, therapy, treatment, and accelerate cures. We are dedicated to establishing a new paradigm of patient-empowerment, through crowdfunding, cutting edge research, and personalized medicine by providing knowledge, human resources, capital, and scientific tools through/in collaboration with scientists from across the globe.