

THORIOVE

The Manifesto for Collaboration

As members of the RARE advocacy community, we understand that we are an integral part of a much larger and growing ecosystem working to effect positive change in the rare disease space. We understand that there have been Herculean efforts by many individuals, organizations, and aligned professionals to lay the foundation that we all build upon today and use to advance progress in rare disease.

As members of the RARE community, we recognize that together we can do more than when we act alone. We acknowledge that the RARE community is a fine and delicate web of initiatives, actions, ideas, and passion that aims to create a brighter future for everyone affected by rare disease. We know that the brightest future will come when we rise as a united community. Most importantly, we understand that when we conduct ourselves in a manner that is collaborative and empowers others, the RARE community truly *THRIVES!*

For these reasons, we commit ourselves to the following RARE values:

THORIOVE

TRUST

- **Trust in the good intentions of my peers.** In times of conflict, we give our peers the benefit of the doubt. We understand that being reactive and judgmental will erode the relationship. Instead, by responding from a place of trust, we can then discuss the potential issue from a place of understanding, rather than asking a peer to defend.
- **Collaborate, and not compete.** Collaboration guards against single agendas, fueling the altruistic outcome that is at the heart of the RARE community. By actively engaging in collaboration, we acknowledge that we are working towards a collective outcome that is greater than what we can do alone and is aimed at serving the entire RARE community with grace and goodwill.

HONEST COMMUNICATION

- **Communicate.** Directly, transparently, and always with altruistic intentions with our teammates, peers, constituents, funders, and partners.
- **Collaborate without competition.** Collaboration guards against single agendas. By actively engaging in collaboration, we acknowledge that we are working towards a humanitarian outcome that is aimed at serving the entire RARE community.

RESPECT

- **Respect my peers and partners.** Respect is reflected in not only our action towards our teammates, peers, and partners, but in the language we use to speak of them. Our words and actions will reflect how we wish for them to treat us.
- **Respect for other organizations' mission, vision and goals.** We are mindful and understanding of other RARE partner goals and work to create positive, mutually beneficial relationships, knowing that there may be the need for compromise.
- **Respect** and acknowledge all of the time, effort, work and passion that has preceded by efforts and helped our organizations' progress.

INTENTIONAL

- **Reflect before reacting.** We understand that there will be times of disagreement. In those moments, we agree to patiently reflect the issue at hand, our role in it and will respond in a manner that aligns with the values set forth herein.
- **Intentionally, be the best version of myself.** Whether in business operations, work efficiencies or interpersonal communications, our actions acknowledge that it is a privilege to serve as an advocacy leader. We are mindful to always engage in a high standard of ethics, business execution, and strategic advocacy contribution, all while exhibiting kindness.

VULNERABILITY

- **Be vulnerable with my peers.** We admit our limitations, insecurities, and worries when we ask for help. We understand that vulnerability is a strength as it allows for deeper connections among individuals that are focused on shared truths and common goals.

ENGAGE & EMPOWER

- **Advocate without borders.** We think, act, and speak with an awareness of the global community we are privileged to serve. We always consider the cultural implications of our words and actions.
- **Empowerment over power.** We acknowledge that true power over another is perceived. We do not grant power to a peer or partner for having more experience, being in the community longer, leading a larger organization, or securing greater financial resources. We understand that rising tides lift all boats, and because of our commitment to a better tomorrow for individuals and their families affected by RARE disease, our actions and words aim to elevate our teammates, peers, and partners.
- **Engage, embrace and be drivers of change.**

We acknowledge that these values serve to elevate the RARE disease community as a whole and help ensure efficient progress towards an inclusive, altruistic goal of creating a better tomorrow for the children, adults, caregivers, clinicians, and fellow advocacy partners engaged in our community.

The undersigned hereby commit ourselves and the organizations we represent to the values stated above.

Name

Signature

Organization Name

Date