

# Connecting Rare Disease PATIENTS

► *Angie Rowe, Interim Executive Director, Global Genes, talks about the 10th anniversary of the rare disease organization and its vision for the future.*

**PV:** Over the past 10 years, what impact has Global Genes had on the rare disease community?

**ROWE:** When Nicole Boice started the organization, her goal was to connect people. She had a good friend whose son's rare disease went undiagnosed for many years and Nicole saw the isolation of this experience. Nicole watched the very long journey to diagnosis and was bothered by the fact that her friend had no way to connect with other parents going through a similar journey.

The goal of Global Genes was, and still is, to connect people to one another so they would not feel so isolated. Well, fast-forward 10 years and those connections and the engagement and inspiration that Global Genes provides to patients and caregivers has taken off tremendously. We've been a catalyst for patients and families to find the power to shape their own future.

We have connected more than 6 million patients and advocates in more than 100 countries. We've educated 75,000 advocates, connected 15,000 rare disease stakeholders, and we have now more than 500 nonprofit partners that we work with through our Foundation Alliance Program.

We're empowering patients to take control of their rare disease journey moving forward. No matter where they are in their journey, Global Genes wants to be their partner in helping them to get the tools and the resources they need to be an advocate or accelerate therapies or start a nonprofit.

**PV:** What are the goals of the organization for the next 10 years?

**ROWE:** The role we play is providing connections, so we aim to continue helping patient communities find one another or be found by researchers or medical specialists or companies that may be working in their disease areas. We want to continue to connect and educate these communities on how to become a player in the process.

The role of patient advocates is vastly expanding; they have more responsibilities and opportunities when it comes to serving their communities. Global Genes will continue to help advocates move forward and to teach them how to leverage data to drive innovation and gain access to therapies.

Some of the groups we work with might only have a few patients, so their voice can be small, but



Angie Rowe

Global Genes aggregates all those voices, and educates all those voices on how to mobilize and be activists allowing for a whole movement to happen. An organization that represents all 7,000 rare diseases has a lot bigger voice and a lot more impact because of the sheer number of people we represent.

**PV:** What is the Patient Impact Grant Program?

**ROWE:** Now in its fourth year, the Patient Impact Grant Program is a funding program exclusively for our Foundation Alliance membership organizations. Member nonprofits have an opportunity to receive a grant to fund their support or innovation projects. Since its inception, we have provided over half a million dollars in funding. Foundation and support groups can join the Foundation at no cost. Our next grant cycle opens in May 2019.

**PV:** How does Global Genes partner with industry?

**ROWE:** We have a corporate alliance that is membership-based. Our corporate alliance and other industry partners provide the support for our major educational initiatives where we bring patients together, such as our annual Patient Advocacy Summit, our Drug Development Symposium that we do in partnership with the University of Pennsylvania, and our RARE on the Road tours that work in partnership with EveryLife Foundation, to name a few. In addition, we work with industry to create opportunities to connect, engage, and build capacity of rare disease patient communities.

**PV:** Tell us about Global Genes' new hub.

**ROWE:** We have a new online portal that launched in February. Our new hub is a way to connect even

## Rare Disease Facts

Although rare and genetic diseases, and many times the symptoms, are uncommon to most doctors, rare diseases as a whole represent a large medical challenge. Combine this with the lack of financial or market incentives to treat or cure rare diseases, and you have a serious public health problem.

- There are about 7,000 different types of rare diseases and disorders, with more being discovered each day.
- 30 million people in the United States are living with rare diseases. This equates to 1 in 10 Americans or 10% of the U.S. population.
- Similar to the United States, Europe has about 30 million people living with rare diseases, and an estimated 350 million people worldwide suffer from rare diseases.
- If all of the people with rare diseases lived in one country, it would be the world's 3rd most populous country.
- In the United States, a condition is considered "rare" if it affects fewer than 200,000 persons. International definitions on rare diseases vary. For example in the UK, a disease is considered rare if it affects fewer than 50,000 citizens per disease.
- 80% of rare diseases are genetic in origin, and thus are present throughout a person's life, even if symptoms do not immediately appear.
- Approximately 50% of the people affected by rare diseases are children.
- 30% of children with rare disease will not live to see their 5th birthday.
- Rare diseases are responsible for 35% of deaths in the first year of life.

more patients and patient communities. People on the hub can identify themselves as a caregiver, a patient, an advocate, and/or a supporter, and they can connect to resources, clinical trials, and other information about different rare diseases and support groups. Patients can also share resources and information about events. The platform allows people around the world to connect, share, and find rare disease information 24 hours a day. **PV**

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