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G-PACT and Genetic Alliance to Collect Feedback for FDA's Patient-Focused Drug Development Initiative

WASHINGTON, DC (April 22, 2015) – Genetic Alliance and Gastroparesis Patient Association for Cures and Treatments (G-PACT) announced the launch of the G-PACT portal today. This portal will enable G-PACT to engage the gastroparesis community in providing the perspectives of people living with gastroparesis to the U.S. Food and Drug Administration (FDA). As part of their reauthorization, in a program called Patient-Focused Drug Development (PFDD), the FDA committed to obtaining public perspective for 20 disease areas in public meetings to be held between 2012 and 2017. Currently, FDA's disease area of interest is functional gastrointestinal (GI) disorders, including irritable bowel syndrome, gastroparesis, chronic persistent symptomatic gastroesophageal reflux despite standard therapeutic interventions, and chronic idiopathic constipation. G-PACT invites all individuals to provide their feedback on gastroparesis at: <https://www.g-pact.org/registry>.

G-PACT customized Genetic Alliance's Platform for Engaging Everyone Responsibly (PEER) system, through which they are engaging in a systematic collection of affected individuals' perspectives on a condition's severity and current unmet medical needs.

"Genetic Alliance is excited to offer the Platform for Engaging Everyone Responsibly (PEER) to capture the perspectives of G-PACT members about the benefit and risks of interventions that are most relevant and important to them," said Sharon Terry, Genetic Alliance president and CEO.

According to Colleen Beener, G-PACT's Operation Director, "Gastroparesis affects about 1 in 25 people, but is a poorly understood disease. There is no cure, and treatment options are limited and mostly ineffective. The opportunity for us as patients to reach the FDA with our needs and concerns is both unique and ground-breaking. We finally have a chance to make our voices heard and help direct research that will help find better treatment options and, ultimately, a cure."

PEER enables G-PACT to give each person dynamic and granular control over their own health information. It is powered by Private Access' innovative technology. Private Access

is a pioneer in developing participant-centric access controls and privacy management systems. Private Access empowers each individual to set meaningful sharing and privacy preferences that reflect his or her needs and interests.

Genetic Alliance also invites other individuals who experience irritable bowel syndrome and chronic persistent symptomatic gastroesophageal reflux to provide feedback at <http://www.geneticalliance.org/GIPortal>.

This project is supported through funding from the Pharmaceutical Research and Manufacturers of America, the Robert Wood Johnson Foundation, Private Access and Genetic Alliance.

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About G-PACT

Gastroparesis Patient Association for Cures and Treatments is a 501(c)(3) non-profit organization which provides services to patients who have a digestive tract paralysis including gastroparesis, chronic intestinal pseudo-obstruction, and colonic inertia. We reach out to over 35 countries and all 50 states. We focus on a variety of options and provide services and information completely free of charge. We are staffed completely by volunteers, so 100% of donations go to support our activities. *For more information about G-PACT visit www.g-pact.org.*

About PEER

The Platform for Engaging Everyone Responsibly (PEER) enables individuals to share health data on their own terms. Individuals set their own data sharing, privacy, and access preferences. With the help of guides from their community, they choose settings that strike a balance between their desire for solutions to their medical needs and their sensibility about privacy. This allows dynamic and granular contextual engagement. *For more information about PEER, visit www.geneticalliance.org/peer.*

About Genetic Alliance

Genetic Alliance engages individuals, families, and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies, and public policy organizations. *For more information about Genetic Alliance, visit www.geneticalliance.org.*

About Private Access

Private Access is striving to make it safe for sensitive personal information such as medical records and genomic data to be accessible over the Internet. Through PrivacyLayer®, the firm's core services platform, Private Access empowers individuals to set granular privacy preferences and use dynamic consent tools to address a number of critical privacy concerns and related hurdles that have traditionally impeded privacy-protective sharing of

this valuable information. In 2009, Forbes named Private Access as #12 on its list of America's Most Promising Companies. *For more information, visit www.privateaccess.com.*