FOR IMMEDIATE RELEASE

Claritas Genomics and Genetic Alliance Announce Partnership to Enable Patients and Families in Clinical Care to Participate in Pediatric Rare Disease Research

BOSTON, Massachusetts -- June 23, 2015 -- Today Claritas Genomics and Genetic Alliance announced a partnership to help patients and families find and participate in relevant research opportunities that will advance understanding of individual genetic disorders and development of new therapies. In this partnership, Claritas, in collaboration with patient advocacy organizations, will use the Platform for Engaging Everyone Responsibly (PEER), created by the Genetic Alliance and Private Access, to connect the patient's genetic test and exome results to their clinical information and enable families to share information between the clinical and research environments, all the while keeping the families' interests at the forefront.

Translational research provides critical information that can illuminate underlying biology and lead to a better understanding of genetic disorders, yet research opportunities are often not easy for patients to find, and it can be difficult to use information gathered longitudinally in the clinical context to continually inform the research enterprise. Moreover, individual patients often do not benefit from research directly, as research is typically performed using de-identified, aggregate data and patients therefore cannot be informed of outcomes. Using the PEER system, patients receiving Claritas clinical testing services can choose what information to share with relevant research initiatives, and receive individualized relevant findings.

"The Claritas mission is to bring answers and resources to children affected with complex genetic disorders, and do so quickly. Now is the time to offer patients and caregivers the opportunity to engage in truly patient-centered genomics research," said Patrice Milos, PhD, Claritas Genomics president and CEO. "We should '*free the patient*' using this system, acknowledging the patient's preferences regarding privacy, risk/benefit considerations, their timeline, and willingness to share their data. Together, let's deliver dynamic and granular consent processes that enable patients to help themselves and others."

"As a parent of two children with a genetic condition, diagnosed after years of diagnostic odyssey and then having to build a research infrastructure for their condition ourselves, I am thrilled that we can offer families the opportunity to easily share their child's clinical and genetic information. PEER allows parents to set their own data sharing, privacy, and access preferences," Sharon Terry, president and CEO

of Genetic Alliance, stated. “This degree of granular and dynamic engagement is novel and Claritas is unique in its vision to enable the patient to remain at the center.”

The PEER participants determine who can see and/or use their data and they can change those settings over time. The participant can also indicate that they wish to be contacted for further opportunities. Communities customize the PEER portal on their website, engaging guides local to the community.

"We have given our patient community, children affected by Joubert Syndrome and related conditions, a unique opportunity to truly participate in research,” said Matthew Smith, uncle of a child with the condition, and board member for the Joubert Syndrome and Related Diseases Foundation. "Those with rare conditions don’t always have a strong voice in medical research advocacy, but the desire is there. We have seen a 3-fold increase in engagement of our community since the launch of our PEER portal in 2014.”

Claritas and Genetic Alliance are excited to partner on this important patient-centric project, giving researchers access to more comprehensive data to accelerate translational science and ultimately alleviate suffering through therapies and interventions.

About Claritas Genomics

Claritas Genomics serves children affected with complex genetic disorders by providing timely and accurate results, resolving families’ long search for answers. By combining clinical expertise of the world’s best pediatric specialists with innovative platform solutions, Claritas is working to improve patient care and enable new discoveries. We are committed to the highest quality and accessibility of information and our interpretive services and unique approach to reporting set the standard for reliably and clearly communicating genetic information. Now is the time to integrate genomics into clinical practice to inform, guide and improve medical treatment for kids around the world. For more information about Claritas Genomics, visit www.claritasgenomics.com.

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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.

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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 about Private Access, visit www.privateaccess.com.

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