

New Global Kidney Platform Where All Participants Have an Equal Voice Now Available

Organizations Focused on Kidney Research Now Have Access to Single, Compliant Platform to Accelerate Discovery of Lifesaving Treatments for Kidney Community

LONDON, ONTARIO, CANADA, March 1, 2023 /EINPresswire.com/ -- Pulse Infoframe is expanding its kidney initiative into a collaborative global kidney platform. This initiative will leverage the company's existing kidney platform, which has an established and growing real-world data set that can be

expanded to support specific research questions for chronic and rare kidney conditions. The platform includes a transparent consent and data-sharing model that will provide both advocacy and industry with an accessible infrastructure to accelerate research in nephrology.

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*Dr. Femida Gwadry-Sridhar,
CEO and founder of Pulse
Infoframe*

“It is important for all participants, from every patient up to each organization, to have an equal voice at the table,” says Dr. Femida Gwadry-Sridhar, CEO and founder of Pulse Infoframe, who has over 30 years' experience in clinical trials, health analytics, clinical disease outcomes and registries.

Dr. Gwadry-Sridhar founded Pulse Infoframe in 2011 because she discovered through her clinical trial experience that medical research operated in silos: each research project collected its own data from study

participants and were challenged sharing data after the study was completed, limiting knowledge dissemination.



This lack of sharing was not necessarily always due to privacy laws, but often, a study's research team simply did not have a secure infrastructure that supported regulatory and security requirements to enable other researchers to safely access the data past the completion of the original study.

Pulse Infoframe solves this problem. First, it helps researchers from multiple industries, including device and diagnostic companies, access much-needed, de-identified data to continue research. Second, it also helps patients contribute to research with minimal effort because their data can be utilized to answer various objectives, where possible—and with their full consent.

In its over 10 years of experience, Pulse Infoframe has developed a way of collecting clinical and real-world data that can be used in every stage of the R&D process, from hypothesis generation to regulatory approval, on a single platform. The company is behind multi-partner patient registries, such as the Global Melanoma Research Network (since 2011), the Pan-Canadian Lung Cancer Observational Study (PALEOS, since 2020), and the Global Uveal Melanoma Registry (OMNI, since 2020). It also powers registries of ultra-rare diseases, like the BHD International Registry for Birt-Hogg-Dubé Syndrome, currently believed to affect only 600 families worldwide.

To support this collaborative undertaking, Pulse Infoframe highlights its partnerships with organizations like QualityMetric, C-Path and Quinten Health, which offer its research, industry and advocacy partners machine learning, artificial intelligence and advanced analytics that create new instruments for measuring disease outcomes and help discover predictive (bio)markers of disease.

For more information, please contact kidneycollaborative@pulseinfoframe.com.

About Pulse Infoframe

Pulse Infoframe is a real-world evidence generation, health informatics and insights company that has built a structured technology and services platform designed to extract, curate, analyze and disseminate evidence-based conclusions that improve the quality of people's lives. Pulse Infoframe provides a full solution for registries, natural history studies and a range of other observational and regulatory grade studies. With provider relationships for patient access, Pulse Infoframe ensures that insights, evidence and publication results are disseminated across the ecosystem, including advocacy organizations, key opinion leaders, researchers, and sponsors. Learn more at www.pulseinfoframe.com.

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