ORF Biologics Launches Rare Disease Program

Coralville, Iowa Sep 17, 2026 (Issuewire.com) - ORF Biologics Launches Rare Disease Program and Biorepository to Accelerate Research and Help Advance New Treatments

ORF Biologics, Inc. today announced the launch of its Rare Disease Program and Biorepository, a new initiative designed to help accelerate scientific research by making high-quality biological specimens and associated research information available for the study of rare diseases.

The program will invite eligible individuals affected by rare diseases to voluntarily contribute biological specimens for research under an Institutional Review Board (IRB)-approved protocol and informed consent process.

The goal is straightforward but urgent: help researchers at ORF Biologics, working in collaboration with researchers globally, gain access to the biological materials they need to better understand rare diseases and develop the next generation of diagnostics, biomarkers and potential therapies**.**

“Rare diseases present a unique challenge because the patients, biological specimens and scientific expertise needed to study them are often dispersed across institutions and communities,” said Sara Ternes, Principal Investigator and Chief Operating Officer of ORF Biologics. “We created this program to help bring those pieces together. By responsibly collecting and preserving specimens and working directly with patients, families, advocacy organizations, clinicians and researchers, we hope to build a resource that enables meaningful scientific discovery and helps accelerate the path toward better diagnostics and new therapeutic approaches for rare diseases.”

Rare Diseases Are Individually Uncommon, but Collectively Are a Major Health Challenge

A disease may be considered "rare" when it affects a relatively small number of people, but rare diseases collectively represent an enormous medical challenge. There are thousands of known rare diseases, many of which are genetic in origin. Collectively, rare diseases affect millions of people in the United States and hundreds of millions worldwide. Yet for many rare diseases, there remains no approved treatment.

The very characteristics that make these diseases rare also creates some of the greatest obstacles to studying them. Patient populations are generally small and geographically dispersed. Individual physicians and research institutions may see only a handful of patients with a particular disorder. Biological samples can therefore be difficult for researchers to obtain, and the limited amount of material available from an individual patient makes every properly collected specimen especially valuable. ORF Biologics believes that a well-organized rare disease biorepository can help address this problem.

Turning Individual Specimens Into a Resource for Discovery

The ORF Biologics Rare Disease Biorepository is being developed to create a carefully managed collection of biological specimens donated by individuals affected by rare diseases and, where scientifically appropriate, their family members. Depending on the applicable research protocol and informed consent, specimens may include blood and blood-derived materials and potentially other biological materials relevant to rare disease research.

When specimens from multiple participants are collected, characterized and maintained within a structured biorepository, ORF researchers will have the ability to investigate questions that would be extremely difficult to answer from an isolated sample.

These specimens may help scientists study disease biology, investigate genetic and molecular differences, identify potential biomarkers, develop laboratory disease models, evaluate potential therapeutic targets and support the development of new diagnostic and treatment strategies. It is our belief that every single specimen will play a role in contributing to a much larger scientific story.

Giving Patients and Families an Opportunity to Participate in Research

For families affected by rare diseases, contributing to research can provide an opportunity to help advance scientific knowledge about a condition that may otherwise receive limited research attention.

Participation in the ORF Biologics Rare Disease Program is completely voluntary and conducted under an IRB-approved research protocol, with an informed consent process designed to explain participation, specimen collection, research use and other information participants need to make an informed decision.

The program is intended to complement, not replace, the relationship between patients and their physicians. Participation does not guarantee that an individual participant will receive a direct medical benefit or that a new treatment will result from the research. Instead, donated specimens may contribute to a broader resource that enables scientists to ask questions that could ultimately improve understanding of rare diseases and help advance future research.

Building a Bridge Between Rare Disease Communities and Researchers

ORF Biologics envisions the Rare Disease Program as more than a repository of specimens. ORF intends to work directly with patients and families, rare disease foundations and patient advocacy groups, clinicians, academic investigators, biotechnology companies and pharmaceutical researchers to help connect rare disease communities with scientists working to understand and treat these conditions. More importantly, the ORF Biologics team of scientists will be conducting internal research studies to better understand the rare diseases being evaluated.

Patient organizations and family-led foundations will play an especially important role. These organizations bring together individuals affected by diseases whose patient populations are otherwise dispersed across the country or around the world. By collaborating with these communities, ORF Biologics hopes to make participation in research more accessible while building scientifically valuable resources that researchers can use to advance rare disease programs.

From Biological Specimens to Better Research

ORF Biologics brings its expertise in biotechnology, biologics research and laboratory operations to the development of the program. The Rare Disease Program expands ORF Biologics mission by creating infrastructure that can help researchers access something that cannot simply be manufactured: biological specimens representing the real human biology of rare disease.

The long-term objective is to help create resources that can support research across the discovery process; from understanding disease mechanisms and identifying biomarkers to developing laboratory models and evaluating potential therapeutic approaches. For diseases affecting very small populations, the ability to responsibly preserve and study specimens today may create research opportunities that would otherwise be lost.

ORF Biologics Is Seeking Participants and Research Partners

ORF Biologics invites individuals and families affected by rare diseases to learn more about opportunities to participate in its Rare Disease Program. We also welcome discussions with rare disease foundations, patient advocacy groups, physicians, academic investigators, biotechnology companies and pharmaceutical companies interested in specimen collection initiatives, research collaborations or access to appropriate biorepository resources. Individuals interested in donating specimens will receive information about the study and informed consent process before deciding

whether to participate.

If you or a family member is affected by a rare disease, your participation could help researchers better understand that disease and contribute to research that may benefit the rare disease community in the future.

To learn more about the ORF Biologics Rare Disease Program, specimen donation, organizational partnerships or research collaborations, contact:

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About ORF Biologics, Inc.

ORF Biologics, Inc. is a biotechnology company supporting life science research through biologics products, laboratory capabilities and research solutions. The company works with researchers and organizations seeking high-quality scientific resources and solutions for challenging biological research applications.

Through its Rare Disease Program and Biorepository, ORF Biologics is expanding that mission by advancing critical research, helping connect patients, families and rare disease organizations with other researchers working to understand rare diseases and seeking to advance future diagnostics and therapies.

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Important Participation Information: Participation in research through the ORF Biologics Rare Disease Program is voluntary. Eligibility, specimen collection, storage, use of specimens and associated information will be governed by the applicable IRB-approved protocol and informed consent documentation. Participation in research does not guarantee a direct medical benefit, diagnosis, treatment, or development of a therapy.

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