



connections newsletter



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UPDATE**

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Lawmakers Hear about North Carolina's Role in Genomic Medicine



Sara Imhof, Jude Samulski, Rep. David Lewis, Jay Griffin, Sam Taylor

NCBIO and BIO hosted a one-hour session at the General Assembly this month to brief lawmakers on Genomic Medicine, including North Carolina's leadership position in bringing new genomic medicines to market. The program included information regarding:

- Health conditions that can be addressed through genomic medicine
- Why North Carolina is a leader in genomic medicine research and manufacturing
- The economic impact and opportunities that genomic medicine companies bring to North Carolina
- The value that genomic medicine brings to a patient and their family
- Access and affordability

Dr. Samulski, Ph.D., Founder of Bamboo Therapeutics and AskBio and Director of the Gene Therapy Center, UNC-Chapel Hill, told lawmakers about the impact gene therapy can have on rare diseases, explaining that "approximately 7,000 rare diseases have been identified and more are being discovered each day." In the United States, any disease affecting fewer than 200,000 people is considered rare.

Samulski also noted that rare diseases affect 30 million Americans, or 1/10 of our population, and 350 million worldwide. "Approximately 50% of those affected are children, Samulski said, noting that "many of these children will not live to see their fifth birthday." "Furthermore," said Samulski, "ninety-five percent of rare diseases do not have a single treatment or cure. Providing better treatments can improve quality of life, prolong life for rare disease patients, and reduce the cost of health care."

Sara Imhof, Ph.D., Senior Director, Precision Health, North Carolina Biotechnology Center, reviewed the economic impact of gene and related therapies in North Carolina. She outlined healthcare, academic and industry collaborations. She noted that announced industry investments in gene therapy research and manufacturing in North Carolina has now reached nearly \$300M. Imhof also discussed the work of the Biotechnology Center's Precision Health Collaborative, which is bringing together health policy thought leaders to discuss the impacts of precision medicine.

Genomics

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Jay Griffin, parent and Duchene Muscular Dystrophy patient advocate, talked about the impact the disease has had on his son and the impact gene therapy could have on patients and their families.

NCBIO President Sam Taylor outlined for lawmakers how North Carolina has become one of the nation's leading hubs for gene therapy research, commercialization and manufacturing. Taylor said, "Our goal for the session was to provide legislators a clear picture of the technologies, companies and positive health care outcomes that have resulted in the Assembly's funding for the life sciences."

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Plant and Animal Production Topics for Caucus Meetings



Dan Jenkins (Pairwise), Rep. Robert Rieves, Tom Adams (Pairwise) and Sen. Mike Woodard

The General Assembly's Life Science Caucus met jointly in June with the Assembly's Agriculture and Rural Caucus. The two groups used the opportunity to learn of new life science technologies promising to bring better crops and improved livestock management to farmers. Guest presenters included representatives of NCBIO members Pairwise and Premex.

Tom Adams, CEO of Pairwise, told lawmakers his company decided to locate in North Carolina because of the diversity of agriculture in the State and the researchers at the universities. He discussed the company's efforts to change where berries and fruits can be grown and research on how to extend shelf life and create other improvements in fruits and vegetables.

Anne Ballou, Lead Scientist at Premex's North Carolina research center, reviewed the company's research on animal health, especially the need to understand the microbiomes of livestock digestive tracts. Among other things, Premex hopes to exploit microbiomes' capacity to stimulate the immune system and improve animal health.

Life Science Committee Co-Chair Senator Mike Woodward (D-Durham), who presided at the meeting, said there would be more joint caucus meetings in the future along with joint trips to facilities in other parts of the State following the General Assembly's session.

NCBIO President Sam Taylor said, "This was a very successful meeting with a lot of good questions about plant and animal research and product development. We look forward to coordinating more joint meetings in the future."

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