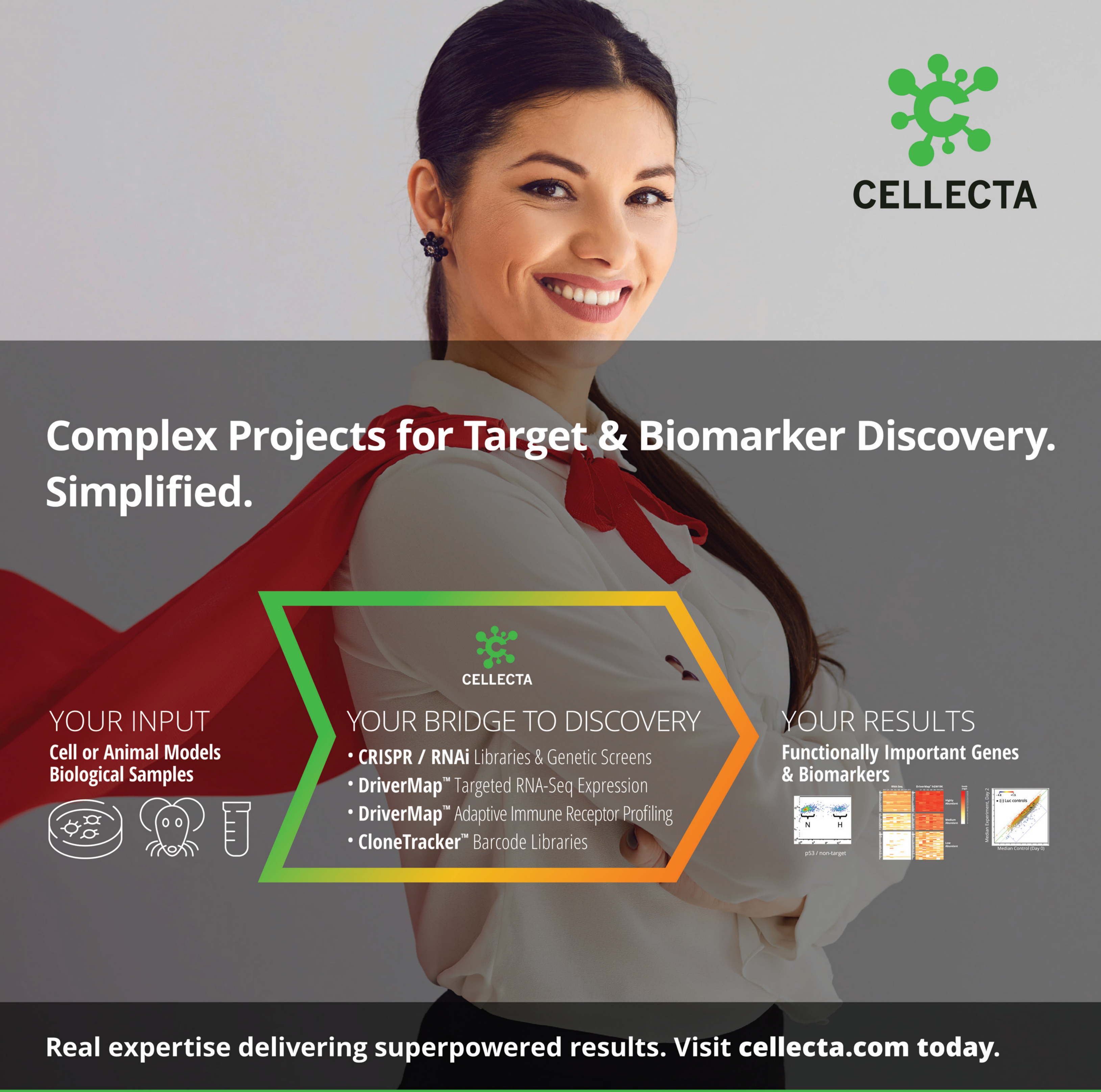

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# MY LIFE, MY SCIENCE

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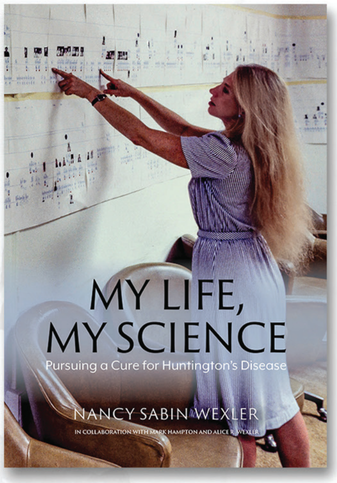

MY LIFE, MY SCIENCE

Pursuing a Cure for Huntington's Disease

NANCY SABIN WEXLER

IN COLLABORATION WITH MARK HAMPTON AND ALICE R. WEXLER

By Nancy Sabin Wexler, *in collaboration with Mark Hampton and Alice R. Wexler*

When Nancy Wexler was 23, her father revealed that the mysterious illness inexorably diminishing her mother had a name: Huntington's Disease, a fatal, hereditary, neurodegenerative disorder. Newly aware she had a 50–50 chance of developing the same condition, Wexler could have retreated. Instead, she immersed herself in what has become a lifetime's pursuit of the causes of the disease and a cure. She pioneered groundbreaking fieldwork that enabled the identification of the responsible gene. She took charge of what is now the Huntington's Disease Foundation and made it a force to be reckoned with. And when the human genome became a focus of scientific study, she was an eloquent voice for patients in disease gene research and insistent advocate for ethical use of genome sequence information.

Now living with Huntington's disease, Nancy Wexler has drawn on decades of diaries, research notes, and vivid memories to tell the powerful story of her remarkable life with warmth, wit, and unsparing honesty. She takes us from a privileged but shadowed California childhood to the shores of Venezuela's Lake Maracaibo, where she and colleagues collaborated with community members to create a massive pedigree of families with Huntington's and collect precious blood samples and clinical information. She introduces us to the innovative consortium of research laboratories where those samples revealed the malevolent gene, leads us into the halls of Congress where she pressed legislators for resources, and invites us into boardrooms where philanthropists were persuaded into action. In this book, Wexler tells a unique story about the intertwining of personal stakes and professional passions, a testament to her courage, persistence, and belief that science can change destinies—one life, one family, one gene at a time.

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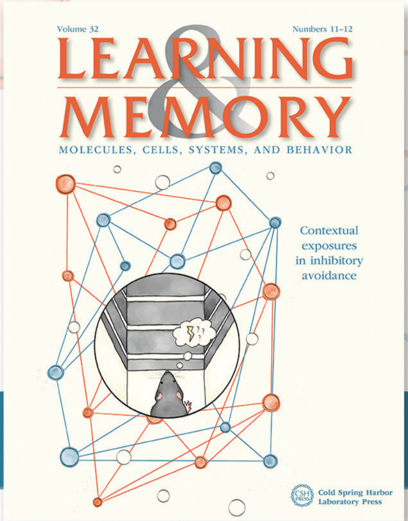

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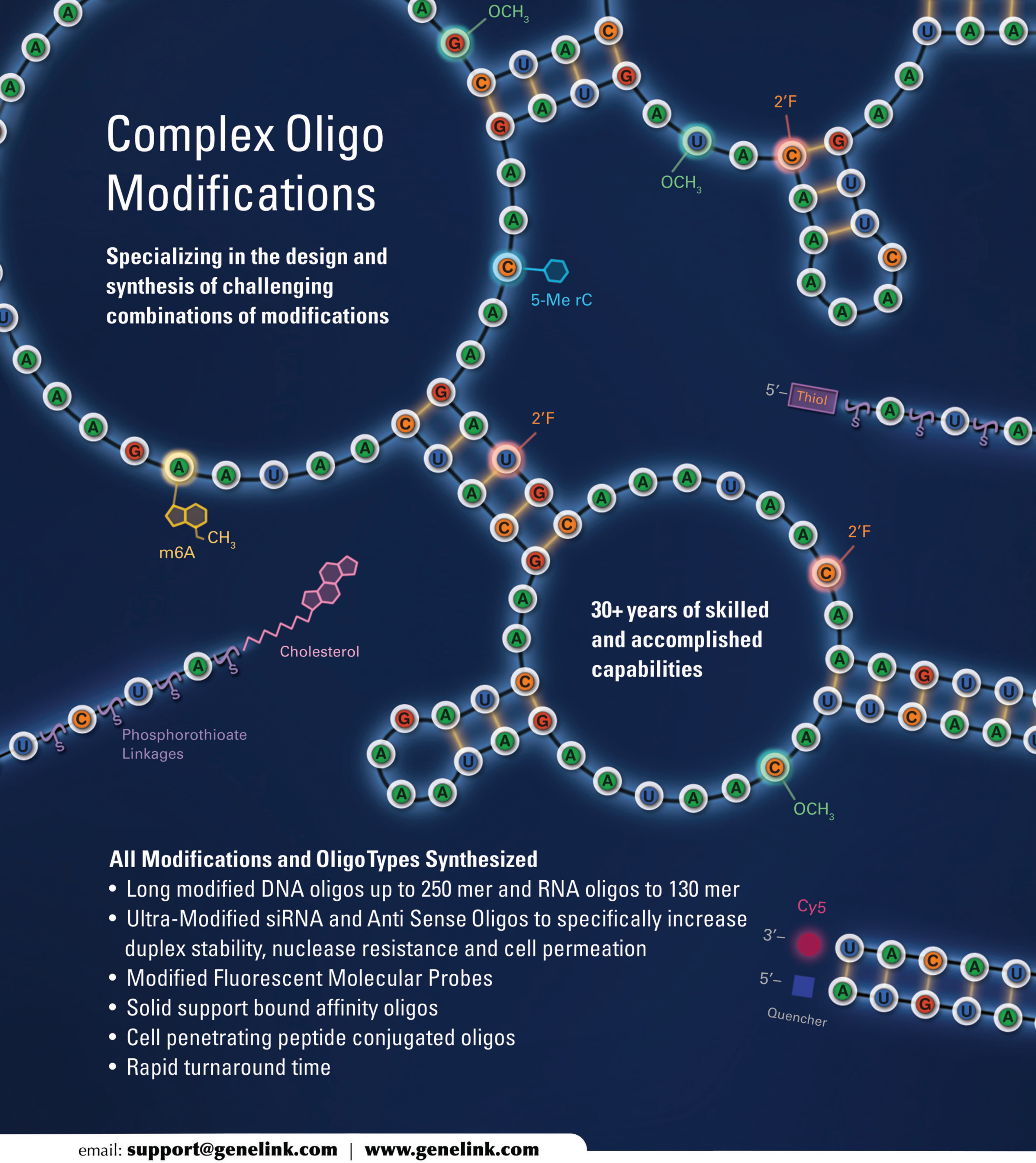

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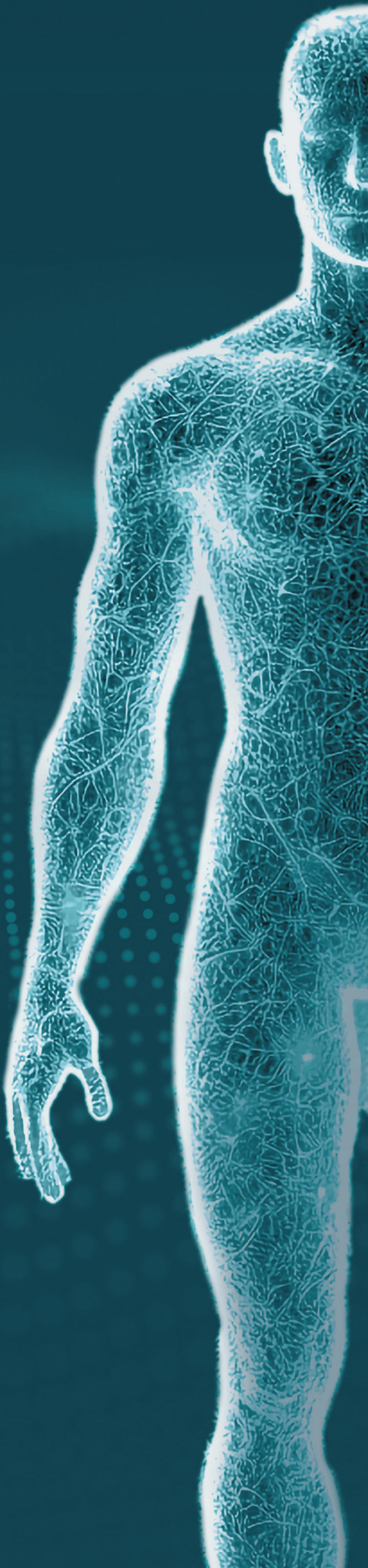

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