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Kathy Moran, MBA

kmoran@acmg.net

Acclaimed Geneticist Dr. Roger E. Stevenson Receives Rimoin Lifetime Achievement Award from the ACMG Foundation for Genetic and Genomic Medicine

BETHESDA, MD – April 3, 2019 | Renowned medical geneticist Roger E. Stevenson, MD, FACMG is the recipient of the **2019 ACMG Foundation for Genetic and Genomic Medicine David L. Rimoin Lifetime Achievement Award**.

Dr. Stevenson, 78, is senior clinical and research geneticist at the Greenwood Genetic Center in Greenwood, South Carolina, where he holds the Curry Chair in Genetic Therapeutics. He is honored for his vision in founding the Greenwood Genetic Center, his groundbreaking research that identified the genetic basis of numerous forms of X-linked intellectual disability, and his leadership in establishing in South Carolina the first statewide program to prevent neural tube defects.

“When I think about Roger I think about his attitude and general approach to his life’s work. I can think of nobody with more brilliance and even greater doses of commitment, integrity, humility, and sheer willingness to put in the countless hours it takes to complete the tasks Roger has taken on,” said Dr. Michael J. Friez, director of the diagnostic laboratories at Greenwood Genetic Center. “And perhaps more importantly, the manner in which he goes about bringing out the very best in those around him. Faculty, staff, and trainees all hold equal status with Roger—each with their own special contribution to moving us as an institution, and as a field, forward. I would also like to acknowledge Roger’s dedication to his family and community where he also commits significant time and energy. He is a true role model on every front.”

ACMG Foundation President Dr. Bruce R. Korf said, “Dr. Stevenson has been a guiding light in bringing the advances of medical genetics to patients in his region and has established an example that is admired internationally. As such, he is a role model for medical geneticists, reflecting the high standards set by Dr. Rimoin, who is memorialized in this award. We congratulate Dr. Stevenson for his careerlong achievements and contributions to our field and to our patients.”

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"Dr. Roger Stevenson's visionary brilliance is reflected in his founding of the Greenwood Genetics Center, a not-for-profit institution that became home to critical research and exceptional mentoring for young geneticists," said Ann Garber, Dr. Rimoin's widow. "As a new concept in 1974, the Greenwood Genetics Center has been an exciting setting for the identification of many X-linked disorders and the prevention of neural tube defects. The Rimoin family is inspired by Dr. Stevenson's mission to move the field of medical genetics toward treatment options for patients suffering from genetic disease and is particularly grateful for his example of leadership through compassion, integrity, and mentorship with his patients and students. We offer Dr. Stevenson wholehearted congratulations as the recipient of the 2019 David L. Rimoin Lifetime Achievement Award."

Upon learning that he had received the David L. Rimoin Lifetime Achievement Award, Dr. Stevenson said, "To me, this is personally overwhelming, but more important is the recognition of the Greenwood Genetic Center's accomplishments over the last four decades. This small institution in rural South Carolina has brought genetic diagnostics and research to the state. What has been challenging to achieve in many states, the Greenwood Genetic Center has accomplished for South Carolina. In some respects, this award is also an acknowledgement that medical genetics need not be contained exclusively in a university setting; that it can exist and thrive in other settings and that students, residents and fellows can thrive in an environment that is not based in a university, be well trained, and take their careers out into the world to be part of the genetics workforce."

Dr. Stevenson's work in medical genetics began more than a half century ago at Bowman Gray School of Medicine—now Wake Forest University School of Medicine—in Winston-Salem, North Carolina. Of his time at Bowman Gray, Dr. Stevenson said, "It was there that I had my first contact with a 'card-carrying' geneticist, Harold "HO" Goodman. Dr. Goodman was from the lineage of American pioneer geneticists William Allan and Nash Herndon. He adopted me early in medical school and allowed me to set up a chromosome lab in his closet, the first chromosome lab at the university, in the early 1960s. The first report of a chromosome abnormality from the university came out of this lab. Other faculty members at Bowman Gray were also supportive, allowing me to study the effects on babies of mothers with phenylketonuria (PKU)."

During his fellowships in metabolism and genetics at the Johns Hopkins University School of Medicine, Dr. Stevenson worked with Drs. Victor McKusick, R. Rodney Howell, and George Thomas, and changed his focus to metabolic diseases, specifically lysosomal storage diseases. "These mentors adopted me and pushed my career along," said Dr. Stevenson. After leaving Hopkins, Dr. Stevenson spent two years working for Dr. R. Rodney Howell on the faculty of the newly formed pediatrics department at the University of Texas Medical School in Houston, Texas—now the John P. and Katherine G. McGovern Medical School at UTHealth, The University of Texas Health Science Center at Houston.

Dr. Stevenson then made what he describes as one of the largest changes of his career, which was to leave academia and establish the Greenwood Genetic Center with longtime colleague Dr. Harold Taylor. "Hal set up the lab technologies while I set up the clinical services," said Stevenson.

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Of this endeavor, Dr. Charles E. Schwartz, senior research scholar at Greenwood Genetic Center said, "Dr. Stevenson returned to his home state of South Carolina in 1974 with the idea of creating a private, non-profit genetic center that could bring the advances in genetics he was exposed to as a fellow under Dr. Victor McKusick to the people of South Carolina. At that time, there existed almost no genetic services in the state. Within a decade, his vision to establish the Greenwood Genetic Center gave rise to an institution much respected for human genetics in the southeast. In the years since, the Greenwood Genetic Center has expanded its reach beyond the borders of South Carolina and is now recognized both nationwide and worldwide, which would not have been possible without Roger's desire to move current advances in medical genetics into the clinical practice of the Greenwood Genetic Center."

"Of all Roger's accomplishments and previous accolades, none stand taller than the Greenwood Genetic Center and the mission for which it stands. As a private, not-for-profit institution in a relatively under-privileged state, Greenwood Genetic Center is a reflection of everything good that Roger stands for and has created for the benefit of the citizens of South Carolina," said Dr. Michael Friez.

Dr. Stevenson is also known for his work to delineate the genetic basis of X-linked disorders that are associated with intellectual disability. As he recalls, "I had the great privilege to be associated with Dr. Charles Schwartz, a molecular geneticist, who wanted to go back to the original families including the family described in the 1940s by William Allan and Nash Herndon, and others described later by Hans Renpenning and John Optiz. Over the years, we had the privilege of seeing almost all of these original families, all with named conditions that had been reported prior to 1980 and were able to map these disorders to the X chromosome and find the genes." Of working with Dr. Stevenson, Dr. Schwartz said, "Roger has always exhibited tremendous empathy for any family or patient with whom he has contact. He always makes the family relaxed and they know that he understands their situation which can sometimes be quite dire. Roger has always been one who believed that collaborating with others was the most effective way to achieve the best results for his patients."

Dr. Stevenson is also credited with establishing in South Carolina the first statewide program to prevent neural tube defects. Of this achievement, Dr. Steven A. Skinner, director of Greenwood Genetic Center, said, "One of Roger's most notable successes and passionate projects has been in the area of birth defects prevention. He began the South Carolina Birth Defects Prevention program in 1992 and since that time the program has led to a 60% decline in neural tube defects within South Carolina and has been hailed as a model prevention program."

On a personal note, Dr. Skinner said that Dr. Stevenson "was an extraordinary mentor. His scholarship in the field, most notably in the areas of X-linked intellectual disability and birth defects, is unparalleled and under his tutelage and guidance, I and many other genetics fellows and residents have developed a passion for the field as well as a compassionate and caring manner in working with patients and families. He sees his work as that of a servant providing care and hope to families struggling with difficult circumstances. He actively avoids the spotlight but is

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quick to point out the contributions of others. Though he would disagree, those of us who are privileged to work with him on a daily basis understand that it was his vision that created the Greenwood Genetic Center and his persistence, will, and sheer determination that has turned it into the success it is today."

Looking forward, Dr. Stevenson has great aspirations for the field of medical genetics. "The most exciting part of all is where we are going. We need to move from a diagnostic specialty to a treatment specialty. For every disorder we are involved with, we should think of how to treat, cure, or prevent it. The mindset of our specialty has to incorporate the ability to treat every genetic disorder, and this will be even more exciting than diagnosis," he said, with gratitude that the Greenwood Genetic Center will allow him to devote the rest of his career to moving in that direction. To achieve this goal he said, "will require worldwide collaboration to develop treatments and places like the Greenwood Genetic Center to bring those treatments to patients."

Of those with whom he has worked, Dr. Stevenson said, "I have had many great mentors in my career, but one thing that has been very important to me has been the contact I've had with students, residents and fellows who have influenced me throughout my career." To all the young geneticists just beginning their careers, Dr. Stevenson offers this, "Taking on this vow of getting us to treatments for genetic disorders is a very important thing. We cannot forget diagnostics because if we do not know the cause of a disorder it is difficult to dream up treatment, but our mindset as geneticists must also include how a condition can be treated."

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The David L. Rimoin Lifetime Achievement Award is the most prestigious award given by the ACMG Foundation. A committee of past presidents of the American College of Medical Genetics and Genomics selects the recipient following nominations, which come from the general membership.

About the ACMG Foundation for Genetic and Genomic Medicine

The ACMG Foundation for Genetic and Genomic Medicine (ACMGF), a 501(c)(3) nonprofit organization, is a community of supporters and contributors who understand the importance of medical genetics and genomics in healthcare. Established in 1992, the Foundation supports the American College of Medical Genetics and Genomics' (ACMG) mission to "translate genes into health"; to foster charitable giving, promote training opportunities to attract future medical geneticists and genetic counselors, to share information about medical genetics, to sponsor important research, and much more. To learn more and support the ACMGF mission to create

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“Better Health through Genetics,” please contact Nicole O. Bell, ACMG Foundation Manager, at nbell@acmg.net or (301) 718-9604 or visit www.acmgfoundation.org.

About the American College of Medical Genetics and Genomics (ACMG)

Founded in 1991, ACMG is the only nationally recognized medical society dedicated to improving health through the clinical practice of medical genetics and genomics. The American College of Medical Genetics and Genomics (www.acmg.net) provides education, resources and a voice for more than 2,200 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals, nearly 80% of whom are board certified in the medical genetics specialties. The College's mission is to develop and sustain genetic initiatives in clinical and laboratory practice, education and advocacy. Three guiding pillars underpin ACMG's work: 1) Clinical and Laboratory Practice 2) Education and 3) Advocacy. *Genetics in Medicine*, published monthly, is the official ACMG peer-reviewed journal. ACMG's website (www.acmg.net) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Resources, and a Find Genetic Services tool. The educational and public health programs of the American College of Medical Genetics and Genomics are dependent upon charitable gifts from corporations, foundations, and individuals through the ACMG Foundation for Genetic and Genomic Medicine.

Note to editors: To arrange interviews with experts in medical genetics, contact Kathy Moran, MBA, ACMG Senior Director of Communications and Public Relations at kmoran@acmg.net.

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