

# Patient Story

## Featuring: Mrs. Mary Northington

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Mrs. Mary Summers Northington was first introduced to me as a Scleroderma warrior, leaving me eager to hear more about her journey. As she generously let her story unfold through back-and-forth emails, it made sense that she would be highly regarded by those around her.

Attending the University of Buffalo Law School during building renovations and a harsh New York winter, she found herself challenged not only by academics, but also by the weather. She experienced Raynaud's which caused her fingers to become cold and numb requiring her to wear battery heated gloves. Carrying heavy textbooks across campus also posed a challenge due to profound weakness in her legs. Several doctors were unable to provide a definitive diagnosis of her condition. When she was around 44 years old a physician friend recommended that she be seen by one of her colleagues, a rheumatologist, Dr. Edward J. Marine. He reviewed her records, took the time to order supplementary tests and disclosed that she had Scleroderma.

At this time, Scleroderma was unfamiliar to Ms. Northington, so she assumed that it was something for which she could be treated and cured. Following her diagnosis, she was encouraged to continue with her usual daily activities and was treated for years with a medication called colchicine. As a result of her condition, she was granted 100% disability by the Social Security Administration where she was able to acquire benefits for her children to assist with her role as a single parent. At one point, she recalls her condition became so severe that she was hospitalized. By this time, her skin had thickened to the extent that she could no longer raise or bend her arms. Phlebotomists could not penetrate to take her blood. Most distressing was the fact that medical support staff who were unfamiliar with the disease rumored that her problems included mental issues. Upon discharge from the hospital, she was bedridden and required personal care while under treatment by Dr. Marine.

Despite her health obstacles, Ms. Northington found it in her to persevere. She utilized vocational rehabilitation services and passed a civil service examination, becoming employed as a research analyst. After formally retiring as a civil servant in 1984, she continued to work as a community health planner, highlighting her work ethic and resilience. Even after relocating to Covington, Kentucky for 18 years to care for her mother she remained under the care of Dr. Marine, who recommended remaining under the care of a teaching hospital. The University of Cincinnati Medical Center explored additional diagnoses other than Scleroderma while continuing her colchicine regimen.

Later she returned to New York State where she now lives close to her children who are able to see that she is comfortable in her old age. Through the years, until his sudden and unexpected death in 2011, she remained in close touch with Dr. Marine. Mrs. Northington remembers with gratitude that even when she was no longer under his direct care Dr. Marine always made himself available to subsequent doctors, including rheumatologists, to apprise them of her medical history. Sadly, none were inclined to use his knowledge to her benefit.

Her involvement with the Tri-State Chapter has been through interactions with the Rochester support group, working to promote knowledge and support activities pertaining to Scleroderma. In addition to Dr. Marine and her support group relationships, she credits her friends and family for helping her throughout her journey. As Ms. Northington connected the dots of her story for me, she was teaching me invaluable lessons along the way. She stressed the importance of being your own advocate, asking questions and persisting in seeking answers. Her story emphasized that listening is crucial to empathizing with and caring for patients, as there is always something to be learned from those around you. While she states her symptoms have gone into remission throughout the years, she continues to leave her mark and pave the way for those that follow with her contributions towards the Scleroderma community.