

Stress Test

Traumatic life events trigger genes.

SCIENTISTS WORKING at the University of Otago in Dunedin, New Zealand, have shown once again that

Rare Opportunity

A disease expert faces a new challenge—business.

WHEN ALLAN RUBENSTEIN, M.D., started the National Neurofibromatosis Foundation 25 years ago to focus on the rare genetic disease, he was lauded. But when he announced that he planned to start a company to find a cure, many were dubious. Drug companies have largely ignored neurofibromatosis, which is characterized by development of tumors along nerves, for several reasons—not the least because its symptoms vary widely across individuals and the tumors' slow growth mean long clinical trials. Undeterred, Dr. Rubenstein's company, Nexgenix, hired its first full-time scientist in July.

At the moment, neurofibromatosis can be treated only by removing the tumors surgically, since they are resistant to radiation or chemotherapy. The trouble is that they grow back. Thanks, in part, to Dr. Rubenstein's efforts, the genetic cause of the disease and much of its pathology have been worked out. This

would seem to give him at least a fighting chance to build a drug for the ailment that affects more than 100,000 Americans.

Dr. Rubenstein might not have experience building a company or making drugs, but he says Nexgenix could soon count on the services of five of the world's leading experts in neurofibromatosis. Still, these experts are waiting for funding to come through and all plan to work from their (different) home cities.

The company is trying to raise an initial \$1.5 million from venture capitalists and angel investors. What do they get in return? If Dr. Rubenstein is on the right track, Nexgenix would tap a market worth as much as \$2.5 billion annually. This is, after all, a chronic condition requiring lifelong treatment. (Presently, that amount is pure extrapolation. But one thing is certain: the market is there.) If Nexgenix could garner even a fraction of that business, its success might motivate more entrepreneurs to take risks—expensive risks—on diseases so bedeviling that even government incentives for research have not been enough to entice industry. —M.B.