

### Researcher is part of team studying rare disease

*"I don't think any of us expected to succeed."*  
— Dr. W. Ted Brown, on discovering the defective gene believed to cause progeria

## Researcher finds cause of rare disease

Doctor at Willowbrook facility slated to close is studying aging affliction that affects children

By DIANA YATES  
SMITHSONIAN MAGAZINE

Dr. Leslie Gordon suspected that her 21-month-old son, Sam, was suffering from a rare aging disorder called progeria. Sam was tiny and had lost most of his hair, two signs of the disease. So in 1999, Dr. Gordon took her son to the only person in the world she trusted to confirm his diagnosis — Dr. W. Ted Brown, then interim director of the Insti-



PHOTO BY PROGERIA RESEARCH FOUNDATION  
Sam Brown, now 6 years old, was diagnosed with progeria in 1999 by Dr. W. Ted Brown.

tute for Basic Research in Developmental Disabilities, Willowbrook.

No one else knew more about the disease, or had seen more children with progeria. Brown confirmed that Sam was indeed affected with



Sam Brown poses with a friend, Miguel, who is also affected by progeria.



PHOTO COURTESY OF NIH  
Dr. Leslie Gordon, who discovered the defective gene believed to cause progeria.

"That gene on its own didn't do anything, but when it came together with another gene, it led to the development of the disease."

Collins predicted that discovery of the gene will lead to the development of the first drug to treat the disease.

### HEALTH & SCIENCE

## Gene tied to aging disorder

Studies find misplaced DNA molecule responsible

By PAUL REICHER  
Associated Press

WASHINGTON — A rare disorder that rapidly ages children, often causing them to die in their teens, has been linked to a single genetic mutation, a finding that may help science learn more about normal aging as well.



PHOTO BY AP/WIDEWORLD  
JOHN TACKETT, 15, speaks about his aging illness in Washington, D.C. Behind him are his parents, Troy and Lynn Tackett.

of 200, which would be the largest and most comprehensive study of the disease.

*The Progeria Research Foundation, Inc.*

1000 14th Street, N.W.  
Washington, D.C. 20005  
Phone: 202-331-1000  
Fax: 202-331-1001  
www.progeria.org

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Author: Les F. Gordon, M.D., PhD  
Professor and Chairman, Dept. of Pathology  
The University of Texas Medical Branch  
Galveston, Texas

PHOTO BY PROGERIA RESEARCH FOUNDATION

## Rapid-aging disease linked to single gene flaw

WASHINGTON — A rare disease that causes children to age rapidly and die in their teens has been linked to a single genetic mutation, a finding that may help science learn more about normal aging as well.

# This State budget will let these kids die at a ripe young age.

  

## Help keep hope alive.

While the news media and scientists throughout the world hail the recent ground-breaking discovery of the genetic mutation responsible for progeria — a tragic illness that causes rapid aging and early death in children — New York State's Executive Budget proposal gives the research facility responsible for this important breakthrough just two more months to live.

The New York State Institute for Basic Research (IBR) on Staten Island has been the home for genetic research for more than 20 years. Dr. W. Ted Brown, co-author of the study on Hutchinson-Gilford progeria syndrome which appeared in the journal *Nature*, spearheaded the research for this devastating illness.

If IBR closes as scheduled in late June, this research and the future benefits of ongoing research will be lost along with research into genetic and environmental causes, prevention

and treatment for birth defects, Alzheimer's disease, and neuro-degenerative disorders in infants and children.

It is short sighted and wasteful to let this exceptional and irreplaceable scientific resource disappear.

**Call your lawmakers today and reverse the cuts in medical research.**  
**1-877-255-9417**

PEF is working with concerned members of the state Legislature in calling for restoration of funding for IBR — a facility within the NYS Office of Mental Retardation and Development Disabilities.

You can help keep hope alive and give these children a fighting chance by calling your lawmakers today.



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