

Hayflick lab faces closure  
By Patricia Wood

Dr. Susan Hayflick – NBIA's top researcher for the past 17 years – said she faces the prospect of closing her lab by the end of this year after being turned down twice in two years for funding by the National Institutes of Health.

Hayflick said she hopes to avert a closure if funds can be found elsewhere, but she realizes the amount is daunting: \$250,000 by the end of the year. She, along with the NBIA Disorders Association, is asking NBIA families, politicians and anyone else who will listen to help.

Hayflick learned in late June that her latest application for an NIH research challenge grant at the Oregon Health & Science University was rejected, and she is fearful her second will suffer the same fate later this month.

In March NIH offered approximately \$400 million in challenge grants to researchers as part of an additional \$10.4 billion designated to NIH with stimulus funds, and were flooded with 18,000 applications. Only 2 percent will be awarded grants.

The rejection comes as NIH did not renew Hayflick's regular grant award for studying NBIA this year. She has applied twice to renew this grant. That leaves her lab without its main source of support. Even if Hayflick applies for a new grant in the next NIH cycle in October, it typically takes two years for the money to flow in. By that time, her lab researchers will have moved on, making it all the more difficult to try and rebuild, she said.

After seeing big increases in research funding between 1999 and 2003, when the budget rose from \$15 billion to \$26.4 billion, NIH funding has been flat in recent years - \$28 billion in 2004 and \$29.5 billion in 2008. President Barack Obama's 2010 budget request is \$31 billion, a 1.4 percent increase over 2009. Sustainable and predictable funding increases for biomedical research are crucial to progress in fighting diseases, but NIH budgets have failed to keep pace with the cost of inflation and conducting biomedical research according to an index used by the government to measure the rising cost of equipment and research workers.

While many researchers are feeling the pressure of lost grants and no doubt some have closed their labs, the loss is much more devastating for the rare disease research community.

As Hayflick put it in a recent letter to the Office of Rare Diseases Research at NIH:

"I write at this time because of the crisis facing the rare disorders community. With NIH extramural funding rates at an all-time low, biomedical research labs are closing. These losses will have little measurable impact on investigator communities in cancer, hypertension, diabetes, etc. But for many rare disorders, the entire research community comprises only one or two investigators. If they are lost, research comes to a halt. Moreover, the investment needed to rebuild from the ground up will be enormous. This is an especially demoralizing time for investigators, and the impact of lost productivity will be hard to quantify.

This crisis is personal for me and will impact members of the NBIA Disorders Association, our family advocacy group. I have been continuously funded by the NIH for 14 years, focusing my studies on this group of rare disorders. My NIH funding has ended and I have little hope for renewed funding in time to preserve the expertise in my lab group. The fallout on the NBIA research community of my lab's closure will be deep and long-lasting. I want to be sure that our friends, colleagues and advocates at ORDR recognize and acknowledge this crisis. We need your help."

Fewer than five researchers devote a substantial amount of their careers to NBIA, so the loss of Hayflick's lab represents a significant loss for the NBIA research community. Her lab was primarily responsible for

finding the first NBIA gene in 2001 and a second in 2006. She directs the NBIA Disorders Association's Scientific & Medical Advisory Board and is considered the leading expert on NBIA in the research community.

The NBIA Disorders Association is mounting a media relations campaign to help make the public aware of the dire funding situation and avert the imminent closure of the Hayflick lab. The goal is to raise \$250,000, which would keep the lab open for two years, at which time it is hoped that funding from the NIH would resume.

The amount is the minimum needed and does not include a salary for Hayflick. The NBIA board still intends to award seed grants through competitive applications in December like it normally would with funds dedicated to our Research Fund.

To raise money for Hayflick, the Association hopes to attract support through publicity on TV shows, newspaper articles and online promotions. We will have a link on our Web site home page at [www.NBIAdisorders.org](http://www.NBIAdisorders.org) for donations to the "Hayflick Lab Campaign." Association Executive Director Luann Rein is coordinating a Facebook cause page where donations will be accepted specifically for this cause. We are hoping NBIA families will start Firstgiving campaigns with their families and friends, and Rein is available to help them with questions on how to set up and use this medium.

If any of you know a media or public relations contact who can help us promote our cause, please contact me immediately at [pwood@NBIAdisorders.org](mailto:pwood@NBIAdisorders.org) or phone me at (619) 588-2315. If you know of any foundations or philanthropic families that might contribute, I would appreciate hearing from you.

Susan Hayflick has been more than a researcher to our families over the past 17 years. She has been a friend, a tireless advocate and our brightest hope for effective treatments and ultimately, a cure. Losing her lab would be an enormous blow to our community, one that would take years to recover from. This is our chance to help her, ourselves and our loved ones.

As we demonstrated in our closing ceremony video at the Fifth International Family Conference in May, "We believe in miracles." Help us make one happen.