

February/March 2010 Newsletter
Hayflick Lab Campaign Update
Well on our way to our goal!

By Patricia Wood

The challenge was daunting: raise \$250,000 to keep open the lab of our premier researcher, Dr. Susan Hayflick at the Oregon Health & Science University, or see it close because of the loss of federal grants.

But here we are, eight months later, and because of your determination, the Hayflick Lab Campaign has raised \$150,690 from NBIA families and friends as of March 10, and OHSU has provided another \$50,000 in bridge funding to keep the lab going. We need just an additional \$49,310 to keep the lab open through 2011. We are hoping the federal funding climate will improve, and the Hayflick lab will receive NIH funding by that time.

Thanks to all of you who donated and who put on fundraisers in your communities. We could not have done this without you.

"I am deeply indebted to the NBIA community and the NBIADA for the remarkable efforts and outpouring of support for my laboratory research program," Hayflick said. "We are forging new collaborations and moving aggressively into new research areas that we think will lead to further federal grant funding. The NBIADA Bridge Funding is a lifesaver, which we hope to repay through new research breakthroughs to help all families with NBIA and related disorders. Thank you!"

Hayflick has committed to keeping the lab open as long as funds are available and says she now has enough funds to operate until mid 2011. She had planned to close in December 2009.

I am hoping that the families that held their first fundraiser this past year will hold another this year and that other NBIA families will join in. Even after we reach our goal for the Hayflick Lab Campaign – we need funds for future research grants. We've all seen what a difference everyone working together can make.

Oct/Nov 2009 Newsletter
Good news: Efforts paying off
in NBIA Hayflick Lab Campaign

By Patricia Wood

I am pleased to report that the outpouring of support for our Hayflick Lab Campaign has been wonderful and we have been making steady progress. Many of our NBIA families have risen to the challenge to raise money to help Dr. Susan Hayflick keep her lab open at the Oregon Health & Science University and have been very busy holding events in their communities this summer and fall.

You may recall in the previous newsletter we brought you the news that Hayflick said she feared she would have to close her lab because of a loss in federal grants that she had routinely received. She said she needed \$250,000 over the next two years to stay open.

I am inspired by the response we received to our call for action and so grateful that many families who have never done fundraisers stepped up and made a big impact. Several of these fundraisers are featured in this newsletter.

As we go to print, the fundraising thermometer on our Web site home page stands at \$66,743, but that doesn't tell the whole story. We have also raised another \$25,000 at various events in October, but that

money is not yet in hand or deposited. We have a few more fundraisers scheduled in November, and we are continually looking for new ways to bring in more. We expect to hit at least \$100,000 before the end of the year.

In addition, Oregon Health & Science University has awarded the Hayflick lab \$50,000 in bridge funding as a show of faith it will continue its research. Hayflick has committed to keeping her lab open as long as funds are available, so we have at least one year funded at this time.

Not only have our families been busy raising funds, but they have made their voices heard on Capitol Hill. A letter writing campaign to senators in states where NBIA families reside, and visits by Hayflick and the Leap family with staff in Washington have made a difference. Our work has paid off with several congressional offices championing our cause, and we are hopeful that the final Appropriations bill will have language regarding NBIA research funding. (see Sandy Leap's article on pg. _1__ for more information.)

We still believe a miracle is possible and that we will find a way to raise the rest of the money. Best of all, this campaign has taught all of us what we can do if we work together. It has showed us that even small efforts can come together to create a big effect.

If you would like to be part of our miracle, please consider sending in a donation in the envelope provided with your newsletter before the end of the year. Mark it for the "Hayflick Lab Campaign" to be sure it gets credited accordingly. We truly appreciate your support.

June/July 2009 Newsletter
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 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 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.