

HAYFLICK'S SPEECH 1ST OF JUNE 2019 AT THE NBIA FAMILY MEETING IN CHARLESTON

About ethics and the type of science Hayflick said:

Hayflick:

"They didn't have the ethics that we require in our partner. One of those is a group in Seville, it's the Braincure group and I will talk to any of you personally about that situation but what I have known about that group for maybe the last four or five years is that their science is very weak, most of it has not been subjected to peer to review. So nobody is checking what they are saying, most of it has not been subjected to peer review and that's all troubling to me".

Reply:

The foundation of the prestigious pharmaceutical Merck Serono (EMD Serono in the United States and Canada) began to support Braincure, so, it will not be as weak a science as Hayflick says.

The researcher who was commissioned for starting the Braincure Project, Professor at the Pablo de Olavide University in Seville, is highly recognized and has a very extensive CV of publications. **ALL PIER REVIEWED:** 145 articles of which, 2, are about NBIA and there is more in the process of publication. See below The CV and the 2 first papers about NBIA.

https://www.researchgate.net/profile/Jose_Sanchez-Alcazar

https://www.researchgate.net/publication/330103811_Precision_Medicine_in_Pantothenate_Kinase-associated_Neurodegeneration

https://www.researchgate.net/publication/327190555_Pantothenate_Rescues_Iron_Accumulation_in_Pantothenate_Kinase-Associated_Neurodegeneration_Dependent_on_the_Type_of_Mutation

He is also an **EXPERT** in **AUTOPHAGY** (important in **BPAN**) and a member of the European TransAutofagy network.

Hayflick:

So there is a claim of remarkable improvement in the health of a person, one of the NBA disorders and that may be truth but it is never been shared with a member of not shared with the scientific community for any kind of critical evaluation.

Reply:

She mixes things and create confusion intentionally.

Hayflick bases her claims on what families in different countries are saying to each other, including Patient Associations, which are also families. That's the only information that Hayflick has about how the Braincure Project is going. What families comment has nothing to do with the formality involved in a research project, which must peer reviewed.

With the comments that families make among us, Hayflick wants peer review of what Braincure Group do.

The Braincure Research Group has been preparing for several months the publication of the clinical results not of 1 patient as suggested by Hayflick, but of 4, and of a first series of patients.

All publications, as up to now, **will be peers reviewed** and will be done when the Braincure Group and scientific journals decide, not when it is convenient for Hayflick.

On the profit and the supposed conflict of economic interests of the Principal Investigator of Braincure Hayflick said:

Hayflick:

“They are now in a profit model and are charging ten thousand Euros, ten and half thousand Euros for their quote service.

They have failed on the conflict of interest because the person who is running that organization, I gaining at least that’s what it looks like. He is an owner of the company and the company makes a profit those profits I imagine goes to the owners of the company”.

Reply:

"at least that’s what it looks like " or " I imagine."

To affirm this, it is needed to have more rigor, you cannot say "at least that’s what it looks like " or "I imagine."

The Patient Associations that are supporting the Braincure Project, ENACH Association Spain, AIDNAI France, NBIA Hungary and NBIA Poland, **all members of NBIA ALLIANCE**, have signed their contracts **DIRECTLY** with the University. They have donated **DIRECTLY** to the University and, the University, issued a Donation Certificate corresponding to each donation and contract.

In each contract signed with the University, the fate of the donations is clearly and precisely stated, so that everything remains under the control of the University without the intervention of third parties.

What Hayflick says is a lie and a reason why possible legal actions that may arise from her unfortunate statements are being studied.