

Clinical trials suffer from “black hole of medical ethics”

The GLP aggregated and excerpted this blog/article to reflect the diversity of news, opinion and analysis.

A decade after Jean Burns was diagnosed with Parkinson's disease, she needed a miracle. Even the drugs of last resort had let her down. Thus, Burns pinned her hopes on an experimental gene therapy study at the National Institutes of Health in Bethesda, Maryland. She knew the treatment would be risky. Surgeons would infuse genes deep into her brain.

However, if anything went wrong, she reasoned, she'd be at a world-class research center, where she would be well cared for. Then Burns read the NIH policy on “research-related injuries,” spelled out on the last page of the 21-page consent form. While the government welcomed her participation in the trial, it said, Burns would receive “no long-term medical care or compensation” if she were injured.

Burns had stumbled into a black hole of medical ethics. There are no rules in the U.S. requiring research organizations to compensate people injured in clinical trials, despite many demands to put such a program into place.

Read full, original post: [Undertake a Clinical Trial at Your Own Risk](#)