

I cannot express enough the **Urgency** and need for interim goal at 2020 or earlier, victims cannot wait for treatment.

**Resources** ... 2020/2025 is goal critical but we need to mobilize the will, the plan and the resource to get there as quickly.

Save time, money and lives, by not reinventing the wheel. Use the finished HIV model. I am a firm believer that the people before us have laid the framework needed to get started so we are not wasting a lot of time on the basics. The only approach I always followed along with that is, to delete, enhance and critique to make the plan even better. Ask the previous plan makers what they did wrong and what would they do different. Ninety percent of that framework came from the best of many minds. I really believe the input and suggestions made by Bruce Lamb, in his letter from January 13, 2012 should be discussed when building this framework.

One thing that keeps coming to mind is the disparity issue related to AD. Am I the only one that sees this, or do we all just not want to talk about it? For example, AD was first identified and named in 1906, while AIDS was identified in 1981. I see us now in the same stages as HIV was in 1988, when a focused effort was begun towards treatment or cure, with the creation of The Office of AIDS Research. It took an additional 5 years to strengthen this OAR (The NIH Revitalization Act), which really made a huge difference. Within three years of that day and by 1996 we started to finally have an impact on AIDS.

Let's not make a similar mistake as we did with HIV. Let's create a disease focused agency for AD, with all the necessary strength, as of day one. Just think you can make up for the disparity that has been created and just maybe we could have a cure in less than 5 years.

**Leadership** ... the President himself needs to speak out because we need everybody at the table - not just Federal government, but industry, research community, victims and affected families, people of all ages -- and only he is in a position to provide that leadership.

Government should consider offering a large sum of money to anyone who can come up with the cure for this disease first. While I am not sure what that amount should be, it can be in cash and partial tax credits. I think that will drive many more into this arena and more efforts if the pie is big enough.

Bruce Lamb shared his viewpoints on January 13, 2012, which were very interesting. I really like these paragraphs below and we should all learn from them. Bruce makes very good points on how to evaluate the adequacy of Alzheimer's funding.

If one assumes that funding for HIV/AIDS was right sized to enable translation of basic discoveries to successful therapies, then given the lack of effective AD therapies, one possible implication is that funding for AD has been insufficient. A quick comparison of funding levels for HIV/AIDS relative to AD in the United States suggests this may be at least one factor that has hindered the translation of AD discovery to effective therapies. Based on publicly available data, National Institute of Health funding for HIV/AIDS in the United States is currently

approximately \$3 billion [5]. With approximately 1 million HIV-positive subjects in the United States, this equates to \$3,000 of NIH funding per person with HIV/AIDs. In contrast, current NIH funding for AD is at a level of approximately \$450 million [5], with perhaps another approximately \$100 million to \$200 million in NIH funding that might have some relevance to the study of AD (cognitive decline in aging, related neuro degenerative conditions). With a current prevalence of approximately 5 million individuals affected with AD in the United States, this equates to a maximum of \$130 of NIH funding per person affected with the disease. So, on a per affected individual basis, NIH funding for HIV/AIDs is 23 times the level of that for AD.

Of course, there are many different ways to evaluate proportional or relative funding. Another one that is quite germane is economic impact. For AD in the United States this is estimated at more than \$170 billion per year (and worldwide at \$600 billion per year) [6]. Again focusing only on the United States, the yearly funding for research by the NIH represents 0.4% of the yearly costs of the disease in the United States. In other words, for every \$2 the disease costs the United States, we spend less than 1 cent on research.

I would like to thank everyone for their hard work to date, but even more important is for you to actually follow through on the promises and plans. I am counting on you!

*Michael Ellenbogen - 53 year old, living with Alzheimer's and trying to make difference.*

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