The Loneliest Activists

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HIV is a disease of the immune system and it is a chronic viral infection. It is two sides of the same coin. The virus side of the equation is not exactly solved, but we have many useful tools and a good and growing understanding of how best to use them. I wish I could say the same for the immune system side, but I can't. While myriad studies of anti-retrovirals (ARVs) continue to be enrolled and reported on, IBTs seem stuck somewhere between bench science and early human studies.

During most of my time at Project Inform, we had an IBT maven- a brilliant, prototypical activist-turned-expert Brenda Lein (who is happily retired). While never lacking for interesting and cutting edge discoveries to talk and write about, most of her activism work was on topics and interventions that were many years away at best from human application. One of our snarkiest activist once went off to me about how, in his organization, there would never be a person working on IBTs- because there was nothing to work on.

He had a point , and he was wildly wrong.

Immune based therapies (IBTs) have been held back by a combination of technical, financial and activist hurdles. While all of these challenges are real and often quite vexing, they are not intrinsically unsolvable; and solve them we must- at least in this writer's opinion.

It is helpful to remember that medicine has cured exactly one chronic viral infection- the Hepatitis C Virus (HCV). Leaving aside the real limitation and drawbacks of HCV treatment, it is nonetheless noteworthy that it has been cured. How? By immune based therapies: interferon and ribavirin. Interferons are a family of immune system proteins, with anti-viral properties. Ribavirin is a widely studied anti-viral drug, that does not exhibit anti-HCV properties in and of itself, but is thought to work by some for of immune system effect.

Both interferon and ribavirin have been studied unsuccessfully in HIV. In fact, ribavirin was one of the first drugs studied against AIDS- showing limited efficacy and significant toxicity.

Our immune systems 'cure' viral infections all the time. Somebody reading this post has a viral infection right now that is being fended off by his or her immune systems. The immune system is highly complex and not well understood. In terms of complexity, it is second only to our central nervous system (CNS). This complexity makes it fertile ground for basic scientists seeking to deepen our collective knowledge, but poses great challenges to drug development.

In HIV one of the most glaring problems is the lack of a clinically validated surrogate marker for immune dysregulation. To study an ARV, viral load and CD4 count are used as surrogate markers

of disease progression. While we know HIV wreaks many kinds of havoc on our immune systems, studying this in detail in the absence of an easy to use and reliable surrogate marker is a problem.

Another problem is the success of ARVs. Prior to establishment of a more-or-less successful anti-viral treatment paradigm (HAART), IBTs were heavily studied- not just in academic centers, but by pharmaceutical companies looking to develop drugs to sell. The success of ARVs has raised the bar so high for the development of alternatives, that the logistic and economics become almost insurmountable. Getting a pharmaceutical company to invest in research and development in this environment is a tough sell.

Many similar problems have been overcome in this epidemic. Activism has been a consistent factor is this- concerted and scientifically sound community involvement from basic science through product development and study has played a part in getting us where we are.

We don’t have the kind of activist presence in the field of IBTs. Richard Jefferies, of NYC’s Treatment Action Group seems to be the lone wolf at this juncture. As smart and capable as Richard is, it is a tough hill to climb alone.

Many activists, including myself- have been put off by the complexity and density of this topic. When I go to ARV meetings, I know what they are talking about- more or less. At immunology meetings, not so much.

There was a time when ARVs were as mysterious to me as IBTs are now- more so in fact. But there were meeting to attend, publications to read and activists to learn from. Where does a less experienced activist interested in IBTs go to learn? What community level publication dose she read? What mentors does he look to?

I am not sure any of this is solvable. I am not sure it isn’t either. I do think that truly solving the problem of HIV infection is going to involve manipulating the immune system, while also treating the virus. I fear we are falling too far behind on the immune based piece of this puzzle, and until we make real progress we will be truly unable to meet the full challenge that HIV poses to us.
