AN AUDIENCE WITH...

Margaret Anderson



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What are the main aims of FasterCures? FasterCures is a non-profit think tank that aims to improve the effectiveness and efficiency of the medical research system. We focus on fostering innovation and accountability across the different research organizations, improving and modernizing the medical research environment, and maximizing the use and development of different research resources.

When we were founded, one of the first things that we did was to identify problem areas in medical research. Then we started to look at successful pockets of innovation and examples of best practices to determine lessons learned. One of the things that *FasterCures* has been successful at is convening the right people from different sectors — such as government, academia, industry and non-profit disease-specific research organizations — to talk about the areas in which things are working well. We try to analyse problems from a different vantage point and we don't have a bias towards any particular constituency.

We always try to look at the patients' role in advancing medical research. That sounds simplistic, but I am constantly surprised by the number of scientific conferences that I attend in which patients are not mentioned. The FasterCures perspective is that if you don't put patients at the centre of research, then the system will slow down. If we don't think about how we can access patients and utilize them effectively, then how can we engage them? Patients' medical records and biological samples are vital in understanding and managing disease, so that is something that we constantly try to put back into the discussion. We have a programme called 'Patients helping doctors' to help maximize their potential. If we don't include patients, if we don't talk to the non-profit disease research groups who are aligned with the patients, then we don't feel that the system can be effective.

What was the aim of the 'Partnering for Cures' meeting that you hosted in December 2009? The goal was to bring together the different parties that work in medical research. such as patient-oriented non-profit organizations — like the Michael J. Fox Foundation for Parkinson's Research and the Multiple Myeloma Research Foundation government, industry, academic medicine, and venture philanthropists. It was a first of its kind meeting, with a programme about the issues that are affecting medical research and a partnering system to enable the ~600 participants to meet face to face. The value of the meeting was the coming together of the different sectors to talk about partnering, to share knowledge and to showcase their research assets. It was also an opportunity to highlight challenges and discuss how they can be collectively addressed.

How are non-profit research organizations working with FasterCures?

Early on in the FasterCures journey, we held a meeting to which we invited representatives from different innovative research organizations. We facilitated a discussion about the barriers to progress that they face and were surprised that each group identified the same problems, independent of the disease area that they are studying. A common complaint was that they are small organizations trying to be innovative and so we created a network called 'The Research Acceleration and Innovation Network' (TRAIN) as a virtual meeting place for them to come together and share experiences. The next phase of this virtual network is TRAIN Central Station (http://www.fastercures.org/train) that will act as a central resource for the entire medical research system to share information.

From discussions with these groups, we also heard that many of them spend time explaining

why they exist to people unfamiliar with the medical research system who think that governments and the pharmaceutical industry should complete the research needed to find treatments for diseases, and, therefore, it is all taken care of. To address this, we produced a document called 'Entrepreneurs for Cures', which characterizes the research system and helps explain why these organizations exist. In addition, we have a philanthropy advisory project for which we have created a series of metrics to analyse such organizations and to help medical philanthropists to appropriately assess their giving opportunities.

How is FasterCures helping research scientists to access resources?

Biobanking is one area that we have paid particular attention to in this regard because we have thousands of samples stored around the globe, but how do we best store, catalogue, access, share and ultimately, utilize them? These are examples of the system-wide issues that we identify and investigate. So, we are in the process of writing a paper that aims to characterize the problems, highlight best practices and point to solutions.

How is FasterCures working with the FDA and the National Institutes of Health (NIH)? I am on the board of directors of the Alliance for a Stronger FDA that tries to get more appropriated dollars from Congress for the FDA from the federal budget. We are looking ahead at the promise of innovation that the FDA will assess, and potentially approve, and the agency needs sufficient resources to do this job effectively. Having a strong, robust and forward-thinking FDA is crucial to getting treatments to patients.

We are also part of the recent discussions about the importance of regulatory science. We are very excited about the recent announcement that the NIH and the FDA will fast-track research and development together in this area, and we see that collaboration as the tip of the iceberg. We think that if you don't connect the translational research that happens at the NIH with the regulatory science at the FDA then you have a wall to climb over. Obviously they recognize that and so it is really exciting to see the leadership at both agencies agreeing that this is a priority.