

HRA: making science open, managed and well-funded

Back in 2015, the Health Research Alliance (HRA), a multi-national consortium of non-profit organisations in the field of biomedical research, announced the selection of **Dr Maryrose Franko** as its new Executive Director. Bringing over 70 non-profit and non-governmental funders of biomedical research together, the HRA is the number one place to go for non-profit organisations seeking to enhance return on their investment in biomedical research. But HRA is about much more than just the “nuts and bolts” of grantmaking. Dr Franko leads the organisation in its commitment to popularising research and taking care of science’s most valuable asset – its people.

Health Research Alliance’s story began in 1998, when a group of private funders met to discuss the role of philanthropy in financing medical research in America.

Some of them later began to meet regularly, which led to the foundation of Clinical Research Alliance. CRA efforts were aimed mainly at gathering data on medical research and sharing knowledge, best practices and experience among its members. But, when the CRA convened over 70 representatives of biomedical research foundations and voluntary health agencies in 2004, they broadened the scope of their activities to include issues that did not fall neatly into the clinical research category. Thus, in 2005, CRA became the HRA which since then, has built one of the largest searchable databases (called the HRA Reporter) of grant awards covering over ten billion dollars’ worth of

available grant-money from 2006 till today, supported young scientists at the early stage of their careers, and advocated for open access to scientific data and publications. Now, with Dr Maryrose Franko, at the helm, HRA is on its way to accomplish even more than that.

Hello Dr Franko! Can you tell us what your role involves as Executive Director of Health Research Alliance (HRA)?

HRA’s mission is to increase the impact of HRA Members’ funding for biomedical research. I facilitate members’ learning in areas like grantmaking and communicating impact. I also do that by making sure HRA gives its members a voice in conversations important to HRA members, thus increasing the openness and reusability of the science we fund – not only publications, but also data and other research outputs.

Our mission and core values are all about maximising the impact of biomedical research to improve human health



I work closely with the co-chairs of each HRA’s Interest Groups to set agendas, convene meetings/webinars, facilitate communication with members of the Groups and conduct research as needed to guide actions. This means I spend quite a bit of time building relationships with members and other organisations with shared goals. I also lead HRA’s communications and its financial management.

Can you also tell us about your additional role as a board member for the Center for Open Science?

As a member of the Center for Open Science Board of Directors, I promote the COS mission, help COS meet all legal obligations based on state law and the by-laws of the board, and maintain financial transparency and accountability for the organisation. We also review annual financial statements making sure that the financial management is sound and we approve the budget. HRA is a strong believer in the value and robustness of COS’s open, public goods model for scholarly communication which is why I was honoured to be invited to serve on the COS board.

Can you tell us about the HRA and briefly outline HRA’s core mission?

In 2005, the HRA was formally incorporated. 21 funders formally joined the Alliance in 2006. Today, we now have almost 80 members, and are still growing!

Our mission and core values are all about maximising the impact of biomedical research to improve human health. To achieve that we collect and share data and analysis about non-profit funding for research and training in the field, address issues key to accelerating its development, and help the research community communicate with funders.

How influential has the HRA been on investment in biomedical research?

HRA does not formally advocate but our members do. The Alzheimer’s Association, for instance, has had a major impact on investment in Alzheimer’s research. They have very generously shared their successful strategies with the rest of the HRA community and some members can already point to increases in funding in their own research space. A rising tide lifts all boats so the fact that we speak with one voice about the importance of biomedical research and work with universities, the NIH, the FDA, and other federal organisations helps to demonstrate the value of investment in biomedical research.

Can you tell us more about the HRA's current plan of action to achieve its mission?

The HRA has a very comprehensive strategic plan. We host semi-annual Members' Meetings which are the principal venue by which HRA members interact, learn, network, and collaborate, and are especially valuable in enabling deep exploration of important issues in basic discovery and translational research.

HRA also has six working groups dealing with common problems in biomedical research like making science more 'open and reproducible', introducing new drugs and therapies, awarding grants, and all kinds of issues young researchers are experiencing at the onset of their careers.

Another HRA's initiative is The HRA Reporter, a real-time, searchable database of awards made by our members. Currently, the database represents over \$10 billion in funding and over 35,000 separate grants from 2006 to the present. Additionally, we use this database to publish reports, like the 2014 report "Bringing Non-Profit Funding of Biomedical Research Into the Light" which provided an enlightening analysis of grants for biomedical research from foundations and grant-making charities.

Dr Maryrose Franko, HRA's Executive Director
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Finally, we publish e-newsletters and other updates to members and the external community about our initiatives, highlights from the Member's meetings, items of interest available on the website, information on upcoming meetings, webinars, and other activities and other information of interest to the membership and the broader biomedical community.

Which organisations have contributed to the and establishment of the HRA and support of its mission?

The engagement of the Burroughs Wellcome Fund, for example, was extremely important in the early days of the HRA, and BWF continues to be one of our very engaged members. The early involvement and leadership of BWF not only was pivotal in creating HRA, but the affiliation with the Fund provided HRA with legitimacy in its early days. The Burroughs Wellcome Fund Board and staff were also instrumental in encouraging private funders of biomedical research and training to collaborate and to share information which resulted in the formation of HRA in 2005.

In addition to increased financial support in the form of ad hoc grants and other support mechanisms, staff members from organisations such as: the Doris Duke Foundation, the Damon Runyon Cancer Research Foundation, the American Cancer Society, the Donaghy Foundation, the Alzheimer's Association, Foundation Fighting Blindness and many more, contribute countless hours of their time toward advancing the HRA mission. This is on top of their very demanding day jobs!

How does the HRA compare to other organisations of non-profit research funders? What makes the HRA different?

HRA is very action-

oriented, so at HRA Member's Meetings, and via the Interest Groups members work together to create valuable resources. We are wonderfully helpful peers – and there is easy access to other HRA members to compare policies and procedures and learn from each others' experiences. We also provide infrastructures such as an ORCID consortium, a portal to enable members open and public access policies, and grantees' access to an HRA-branded data repository. We have also developed the only database of non-profit funding of biomedical research, so the inclusion of organisation's awards in the HRA Reporter database is valuable. Organisation's award data becomes part of an aggregate analysis of philanthropic biomedical research funding which is an important resource for HRA members for landscape analysis and benchmarking, but also for the broader scientific community. Membership also comes with free participation in two Members' Meetings a year that cover both cutting-edge science and policy topics, and nuts & bolts advice.

Do you think biomedical research receives as much funding as it should and what are ways of improving this?

Of course, biomedical research could never receive as much funding as it should. Funded generously or even adequately, it could not only significantly improve human health and longevity around the globe but can also increase our quality of life. It also has the potential to be an economic driver for not only communities but for individuals as well.

We need to recognise the value of robust and rigorous science and put in place infrastructure to encourage and reward thorough science. We need to celebrate science and scientific researchers. Philanthropy, researchers, academic institutions but also the government should play an important role in this celebration. Celebrations of scientific accomplishments and accomplished scientists should be as widely publicised as celebrations of teams

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winning the Super Bowl or the World Series. We also need to help scientists become better at communicating the value of science. Everyone should be able to name an influential scientist (still living!) just like everyone can name an athlete or an actor. If the general public recognises the value of biomedical research then we won't have to fight as hard every year to increase budgets for NIH, NSF and other funding for biomedical research. This is not something that the US should skimp on. For starters, we need to help the American public understand that investment in biomedical research is both an investment in the US economy and an investment in the future of our kids and grandkids.

From a personal perspective, are there any achievements you are particularly proud of?

When I was a member of HRA (long before I was the Executive Director), I co-founded HRA's Early Career Scientist working group, which has evolved into the Research Workforce and Early Career Development Working Group. There are so many thorny issues that affect the research workforce and HRA members are tackling many of these by implementing strategies and measuring outcomes. These are very hard issues (lack of diversity especially in senior positions, lack of opportunities in the academic setting, physician-scientist shortage, inappropriate

reward structure especially in academia, flat NIH funding and low success rates especially for early career investigators, training that doesn't train for 21st century job landscape, etc.) but HRA along with HRA members are working to have an impact where we can.

I am also very proud to be part of HRA's very important Open Science efforts. I personally believe that funded research needs to be open so patients and families can make informed decisions, and boards/donors are able to evaluate the impact of funding. Even more critical is the requirement that resulting data be published in an easily accessible and machine-readable format to enable reuse and analysis by other researchers. Only then can the impact of the funding be multiplied – increasing the potential for significant and far-reaching advances and scientific innovation. HRA's Open Science Task Force is making great strides in providing advocacy and resources to organisations that wish to and can move toward funding science that is more open.

What are your hopes for biomedical research improving human health in the future and how will HRA's research funding strategy play into this?

HRA doesn't fund research itself, so we don't have a funding strategy. But I would like to see PhD scientists trained and opportunities

created so that they can use their training to contribute to the advancement of human health in ways other than as academic professors.

I also would like to see widespread open access to publications and other research outputs, as the ability to access and reuse research data, materials, and other research products have become even more vital to advancing science.

One last area where I think HRA might have an impact is on Health Services Research. In an *Annals of Internal Medicine* article, the authors determined that "On the basis of contemporary data from 2009 to 2013, the median age of survival of patients with Cystic Fibrosis in Canada was ten years greater than in the United States (50.9 vs. 40.6 years, respectively). The adjusted risk for death was 34% lower in Canada than the US". This is disturbing and something that is not addressed by traditional biomedical research, but is an area where we might be able to leverage contacts and resources. This is a new initiative so how much we can impact this area remains to be seen. HRA hopes to address the disparities in outcomes linked to address and not genetic code.

• To find out more information about HRA and their tremendous support for biomedical research, please visit their website at www.healthra.org.



Contact

Maryrose Franko, PhD
Health Research Alliance
P.O. Box 13605
65 T. W. Alexander Drive
Research Triangle Park,
North Carolina 27709
USA

E: maryrose@healthra.org
T: +1 240 393 2968
W: www.healthra.org

