

## **Jessica Hobart**

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Jess Hobart has been involved in advocating for the needs of patients with the rare disease, mastocytosis, since 1996 when she first met others with the disease. She has served on the board of The Mastocytosis Society, where, as Chair for Research, she launched a fundraising campaign to provide grants to researchers and established a network of researchers who collaborate to move the mastocytosis research agenda forward. She has represented mastocytosis patients at research conferences and meetings of medical specialists and has advised established and start-up drug companies on study design for the mastocytosis community. Most recently she served on the Institutional Review Board that assessed the guidelines establishing the Genetic Alliance Biobank, a cooperative biological samples and data repository that allows lay advocacy and community organizations to bank and manage samples and data. She is currently working toward a master in public health at Johns Hopkins' Bloomberg School of Public Health.

In her "day" jobs, Ms. Hobart has helped to establish and has managed a new research center on human rights at Harvard's Kennedy School of Government, where she also worked to raise awareness about the threat of nuclear, chemical and biological terrorism in the era before 9/11. She has worked as a consultant for a research center in Ukraine and for a Brookings Institution/Council on Foreign Relations study on funding for foreign affairs and has created a board of expert advisors for a BBC/NPR program on world affairs. She holds a master in public policy from the Kennedy School and graduated Phi Beta Kappa and with High Honors from Swarthmore College where she studied religion and political science.