

Advancing Research, Support and Advocacy for Metastatic Cancer – First Year Cancer Moonshot Update

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Cancer Moonshot Commitment

METAvivor pledge: Award \$1 million in stage IV cancer research grants in 2017 and \$2 million in 2018.

What is METAvivor

Metastatic breast cancer (MBC) patient founded and led 501(c)(3) non-profit.

Primary Mission: Fund research to increase longevity with enhanced quality of life for stage IV MBC patients.

Additional missions: Support and advocate for stage IV patients. Educate others on stage IV cancer. Train patients to advocate for themselves.

METAvivor Research Program 2009 – 2016

2010: Awarded first research grant: \$55,000 goes to Danny Welch, PhD. Project: KISS1 Metastasis Suppressor Gene. Funds raised through yard sales, holiday home tours and races.

Total awarded 2009-2017: \$2.4 million METAvivor puts 100% of every donation into its research grants.

Progress to Date

2017 Grant Cycle: \$1 million promised. \$1 million has been raised.

Applications: More than 200 Letters of Intent received. **156 full proposals were invited**. METAvivor's Scientific Review Board (metastasis researchers, oncologists, patient advocates) convenes in August. Grants announced Oct 2017.

Amount of Awards: 2017 awards are pilot grants of. \$50,000 to get exceptional ideas off the ground, and \$200,000 grants for concepts showing significant potential

Plans Underway

Appalled at the paltry (5%) level of metastasis research in the Western World*, METAvivor was founded to change that percentage and support the stage IV community. Further inspired by Cancer Moonshot, this year METAvivor studied key issues, took on seven critical goals and established a roadmap to identify and target strategies to achieve them.

*European Journal of Cancer 46 (2010) 1177-1180

Strategic Goal #1

Expand the stage IV cancer research portfolio at the National Institutes of Health (NIH) in FY 2017/ 2018 through growth in appropriations and demonstrated congressional interest in controlling/eliminating cancer that has already disseminated (metastasized).

Steps Taken: METAvivor spearheaded the signing of a letter from Congress to the Director of the NIH, asking for an accounting of their metastasis research. The goal is for the NIH to prioritize research for stage IV cancer. Response focused largely on prevention of metastasis. Further clarification has been requested.

Strategic Goal #2

Ensure the continued growth of the Breast Cancer Research Program (BCRP) within the Congressionally Directed Medical Research Program (CDMRP) at the DoD in FY 2017/2018.

Steps Taken: In October 2016 and April 2017 METAvivor organized and led "On the Hill Days" for stage IV patients and metastasis researchers from all over the US. Meetings were held in over 40 legislative offices to promote inclusion of stage IV research in the BCRP.

Strategic Goal #3

Conduct a sustained outreach and education campaign to ensure members of Congress have the appropriate information about metastatic cancer and the issues facing affected constituents.

Steps Taken: This year METAvivor launched the new Sea to Sea for MBC. We are now traveling throughout the US raising metastasis awareness and educating health officials, legislators, medical staff and the public on important stage IV cancer issues.



Strategic Goal #4

METAvivor is pro-active in efforts to end the waiting period for disability benefits for the terminally ill to include advocating for the Social Security Disability Fairness Act (H.R. 5347/ S. 2010) and addressing concerns with the Medicare Part B Demonstration Project and the 2-year post-SSDI effective start date for Medicare.



Strategic Goal #5

Monitor and inform ourselves and others on relevant legislative and public policy issues by participating in coalition advocacy activities and attending events on Capitol Hill.

Strategic Goal #6

Cultivate a nationwide network of grassroots advocates who will effectively engage their elected officials to help advance the metastatic cancer agenda. Steps taken:



Strategic Goal #7

Participate in community advocacy efforts focused on improving the drug development pipeline and facilitating treatment development.

METAvivor Research Priorities

METAvivor solely funds research focused on benefitting the already metastasized patient. While prevention and early detection are worthy goals, billions of dollars have been put into these endeavors over the past 20 years with no notable impact on most cancers.

METAvivor is partnered with the Metastasis Research Society and works closely with its members, attending its conferences and visiting research laboratories.



METAvivor Research Program: Locations of our 34 grant recipients to date

- Case Western
- City of Hope
- Cleveland Clinic
- Columbia
- Huntsman
- Houston Methodist
- Johns Hopkins
- Loyola
- MD Anderson
- Michigan State
- NCI
- Oklahoma Medical Research Foundation
- Penn State
- Princeton
- Purdue
- Rush University
- Stanford
- Texas Southwestern
- Universities of AL, CO, MI, MN, NE, SC,
- Vanderbilt
- Virginia Commonwealth

Conclusion

To meet its Moonshot commitment, METAvivor has raised \$1 million to fund stage IV cancer research projects in 2017 and is well underway to meet its \$2 million Moonshot commitment for 2018. It has also increased its grant program in size and scope.

Also, in 2017 METAvivor launched a strategic plan containing seven critical goals that will benefit the entire stage IV patient community and their families.

Finally, METAvivor and its supporters testify throughout the year on various topics on Capitol Hill. We are very active locally with legislators in their home states.

Patients ourselves, we are highly motivated.