



## CUP Patient Experiences Survey Key Findings

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### Introduction

Cancer of unknown primary, or CUP, is among the 10 most common malignancies in the developed world, affecting about three to five percent of all cancer patients<sup>1,2</sup> -- the equivalent of 30,000-50,000 new cases each year in the United States alone.<sup>3</sup> According to Lenzi, et. al., patients with CUP have a "generally unfavorable prognosis ... [however,] the psychosocial adjustment and QOL of patients with CUP has received minimal empirical attention." We fielded a survey to members of the Association of Oncology Social Work SWON listserv during early 2009 to explore the psychosocial impact of a CUP diagnosis; 140 of the 900 members responded. We designed the survey specifically to assess: how frequently oncology social workers (OSWs) encounter patients with a CUP diagnosis, the distress that this diagnosis causes for patients beyond the initial cancer diagnosis, and the degree to which OSWs feel prepared/equipped to help their CUP patients.

### Key Findings

CUP is a common clinical issue for oncology social workers

- 80 percent of OSWs see CUP patients at least several times a year
- More than 40 percent see at least 10 CUP patients per year

Patients with CUP experience more distress than cancer patients who have received a definitive diagnosis

- According to the OSWs surveyed, the majority of CUP patients (81 percent) feel more distress than patients with a definitive cancer diagnosis
- Specifically, 39 percent of OSWs felt that a CUP diagnosis is significantly more distressing/extremely distressing and 42 percent felt it is more distressing than even a specific cancer diagnosis.

CUP patients face – and are negatively impacted by – unique psychological and clinical issues

- OSWs believe that the three greatest challenges faced by patients diagnosed with CUP are "general fear associated with battling something unknown" (38 percent), "lack of a definitive best therapy for them" (37.3 percent) and "frustration and/or anger that their cancer can't be identified" (21.1 percent).

<sup>1</sup> N. Pavlidis, E. Briasoulis, J. Hainsworth, F.A. Greco. Diagnostic and therapeutic management of cancer of an unknown primary. *Euro J of Cancer*. 2003; 39:1990–2005.

<sup>2</sup> Varadhachary GR, Abbruzzese JL, Lenzi R. Diagnostic strategies for unknown primary cancer. *Cancer*. 2004;100:1776–1785.

<sup>3</sup> S. Becker, Identifying Tumors of Uncertain Origin. *Ad for Admin Lab*. 2008;15:58.

CUP patients face – and are negatively impacted by – unique psychological and clinical issues (cont.)

- Ranking the intensity of challenges faced by CUP patients on a scale of 1 to 10, the OSWs surveyed rated “lack of definitive best therapy” an 8.6, “general fear of battling something unknown” an 8.3, “lack of prognosis or predicted therapy outcome” an 8.1, and “frustration and/or anger that their cancer can’t be identified” a 7.8.

Educational and supportive resources tailored to CUP are either not available or not well-known

- The OSWs surveyed noted that it is difficult to find other CUP patients or a disease-specific organization with which to connect their CUP patients for support and information

Despite the prevalence and serious psychological impact of CUP, OSW professionals are not well-trained to address this condition

- Thirty-four percent of survey respondents say they feel their initial training left them only “minimally prepared” to address the distress experienced by CUP patients; 31 percent say they feel they were “moderately prepared”
- Only 20 percent of OSWs feel “well” or “very well” prepared by their initial training to address CUP patients’ distress

OSWs want information and resources to better support their CUP patients, and have clear information and training preferences

- In order to better provide services to patients with CUP diagnoses, OSWs said they need best practice information from other OSW professionals (85 percent), information about resources designed specifically for CUP patients (77 percent) and information about how oncologists approach medical treatment for CUP patients (75 percent)
- Fifty percent of OSWs said that, in terms of CUP training and information, they have benefited from tumor boards/tumor conferences; 43 percent relied on their own reading and research; and just under 41 percent have benefited from peer/team discussions

Findings from this survey validate the need for oncology professionals to create information resources and networks that will address specific, identified gaps in psychosocial support for current CUP patients. Clinical adoption and application of emerging molecular diagnostic tools should also be accelerated to help reduce the total number of patients who receive “uncertain” and “unknown” cancer diagnoses.

### **About the CUP Patient Experiences Survey**

bioTheranostics, a company specializing in molecular diagnostics for oncology, developed the CUP Patient Experiences survey with input and guidance from the Association of Oncology Social Work (AOSW). An independent research company fielded the survey via email among the entire AOSW membership during the first quarter of 2009, and tabulated information from the 140 total responses.

For more information about the CUP Patient Experiences survey or bioTheranostics, please contact Michele Parisi at 925/429-1850 or mparisi@biocommnetwork.com